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Equipping Renal Patients to Make Treatment Decisions: the Use of Self- Efficacy Theory to Guide Development of a Pre-Dialysis Educational Intervention.

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A thesis submitted in partial fulfilment of the requirement
for a degree of Doctor of Philosophy in Health Science

University of Warwick
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Abbreviations

| | |
|------------------------|---|
| AR | Action Research |
| CI | Confidence Interval |
| CKD | Chronic Kidney Disease |
| CNS | Clinical Nurse Specialist |
| DI | Decilitre |
| DoH | Department of Health |
| ED | Education Day |
| eGFR | Electronic Glomerular Filtration Rate |
| EPO | Erythropoietin |
| ERF | Established Renal Failure |
| GFR | Glomerular Filtration Rate |
| Hb | Haemoglobin |
| HCP | Health Care Professional |
| HD | Haemodialysis |
| HRQoL | Health Related Quality of Life |
| Kt/V | Dialysis Adequacy Marker |
| KPA | Kidney Patient Association |
| MDT | Multidisciplinary Team |
| MRC | Medical Research Council |
| Needs Assessment Study | Retrospective Patient Views of Pre-Dialysis Education: A Needs Assessment Study |
| NHS | National Health Service |
| NS | Not Significant |
| NSF | National Service Framework |
| OR | Odds Ratio |
| <i>P</i> | Probability |
| PAR | Participant Action Research |
| PCKD | Polycystic Kidney Disease |
| PD | Peritoneal Dialysis |
| Pre-Dialysis | Service Users Pre-Dialysis and Treatment Decision– |

| | |
|-------|-------------------------|
| Study | Making Experience Study |
| PtDA | Patient Decision Aid |
| QoL | Quality of Life |

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Declaration

The material included in this thesis is all from my own work. None of this thesis has been published in another form, or submitted for a degree at another university.

K. McCarthy

January 2014

Abstract

Introduction: People with established renal failure have difficult treatment decisions to make. Pre-dialysis education that leads to treatment decision-making has traditionally been ad-hoc, with programmes lacking a theoretical or evidence basis. The two key aims of this study were to design and deliver a theory-based pre-dialysis educational intervention and explore individuals' pre-dialysis experience. Understanding the interplay, between the two, informed recommendations about how best to intervene to help people make good treatment decisions. The MRC Complex Intervention Framework guided study development but it has only been possible to address the first two phases within the scope of this thesis. Subsequent phases will be the focus of post-doctoral research.

In the **Theory Phase** renal and long-term condition self-management literature was reviewed and self-efficacy theory was predominant in the literature. To address a significant gap identified in the literature the 'Retrospective Patient Views of Pre-Dialysis Education Study' sought 29 participants perspective of pre-dialysis educational components, using semi-structured interviews. Clinicians' advice and written information were valued and unplanned vicarious learning began to emerge.

The **Modelling Phase** was founded on the theory phase findings. Firstly, a multidisciplinary and service user Participant Action Research study developed and delivered a self-efficacy theory-based pre-dialysis education intervention. The 'Service Users Pre-Dialysis and Treatment Decision-Making Experience Study' explored 20 participants pre-dialysis year, at 3 time points, resulting in 54 interviews. Findings were analysed using a grounded theory approach revealing that vicarious learning, the clinical setting and written information influenced treatment decision-making.

Conclusion: Decision-making is dynamic and requires dynamic educational inputs tailored to individual needs. The 'Conceptual Model of Influences Impacting the Pre-Dialysis Journey' brings together the themes emerging from the grounded theory analysis. From this the original contribution to extending self-efficacy theory was developed, namely that vicarious learning and not mastery is key at this stage of individuals' care journey and this has not previously been recognised. The practical output from the research is the 'Pre-Dialysis Education Curriculum'. Recommendations for future research include an exploratory trial of self-efficacy theory-based pre-dialysis education.

Chapter One:

Introduction

Chapter One: Introduction

The pre-dialysis journey for individuals with renal failure is unique in the field of chronic disease healthcare. Individuals with non-reversible renal decline are required to make decisions about the renal replacement treatment that will extend their lifespan. There is clinical equipoise about treatment options, however. There are extensive implications for individual functioning and radical lifestyle ramifications.

The literature on self-management educational interventions illustrates the need for further research on the role educational interventions play in the field of pre-dialysis education and treatment decision-making. The thesis will focus on the participants' perspective and experience of the pre-dialysis journey and treatment decision-making. The influences affecting the pre-dialysis journey and its bearing on treatment decision-making will be explored including:-

- The role of learning theory and health policy informed pre-dialysis education will be sought. Participants' views on the type of intervention, the different educators and the intervention delivery methods will be explored.
- Factors influencing participants' self-efficacy, and impacting upon individuals' ability to cope and adjust over the pre-dialysis period, will be considered.

- The pre-dialysis elements impacting on individual treatment decision-making will be considered.

Setting the scene

Classification of Chronic Kidney Disease (CKD)

Classification of renal failure is based on glomerular filtration rate (GFR).

GFR is calculated using individuals' serum Creatinine level, age, gender and ethnicity. The classification of Chronic Kidney Disease Stages (CKD) is illustrated in Table 1.0.0

| CKD Stage | GFR | Description | Treatment Stage |
|-----------|------------|--|---|
| 1 | 90+ | Normal kidney function but urine or other abnormalities point to kidney disease | Observation, control of blood pressure |
| 2 | 60-89 | Mildly reduced kidney function, urine or other abnormalities point to kidney disease | Blood pressure control, monitoring, find out why. |
| 3 | 30-59 | Moderately reduced kidney function | More of the above, and probably diagnosis, if not already made. |
| 4 | 15-29 | Severely reduced kidney function | Planning for end-stage renal failure |
| 5 | 14 or less | Very severe, or end-stage kidney failure (sometimes call established renal failure) | Treatment choices for end-stage kidney failure |

Table 1.0.0 Chronic Kidney Disease Stages (K/DOQI 2002)

Detection of Chronic Kidney Disease

Automatic reporting of GFR, known as estimated Glomerular Filtration Rate (eGFR), was introduced by the Department of Health (2007a) to reduce the

number of renal failure cases missed in general practice and increase early referral to nephrology. Whenever a serum creatinine measurement is requested this provides clinicians with an eGFR and indicates any issues with renal function. The UK guidelines for identification, management and referral of CKD in adults were produced by the Royal College of Physicians to support the introduction of eGFR (2006). Further impetus has seen four renal domains added to the Quality Outcomes Framework for the management and to encourage the development of CKD registers in primary care (Dept of Health 2006c). Detailed guidelines for primary care physicians exist to: offer testing for CKD if risk factors exist, identify and treat progressive CKD, and referral for specialist assessment (NICE 2008).

One of the main objectives of eGFR reporting is the avoidance of late referral of individuals with CKD to nephrology services. Patients referred to nephrology services less than three months before treatment commences are considered to be acute and these patients constituted 19.4% of referrals, compared with 67.1% presenting over a year before dialysis is required (UK Renal Registry 2009). The proportion of late presenters has steadily declined since 2005 and this is believed in part to be due to eGFR reporting and QOF implementation (UK Renal Registry 2009). The average eGFR at the start of dialysis is 8 (www.edren.org [Accessed] December 2009).

Prevalence and Treatment of Chronic Kidney Disease

The estimated prevalence of patients on dialysis or with a functioning kidney transplant is 774 per million of the population, equating to 47,525 individuals

(UK Renal Registry 2009). A steady rise is predicted to continue for the foreseeable future and continues currently at approximately 4.4% per annum (UK Renal Registry 2009). Currently over 2% of the total National Health Service budget is spent on dialysis and kidney transplantation (NICE 2007).

This study is set in a large multicultural urban conurbation with a catchment of 1.3 million people. Fifty-six per cent of patients start on haemodialysis, 24% on peritoneal dialysis, and 11% are transplanted, reflecting the hospital's regional transplant centre status. Nine per cent of patients are deceased at 90 days post commencement of treatment, and these figures reflect the national picture (Renal Registry 2009).

The treatment options for Established Renal Failure (ERF) are transplantation, haemodialysis (HD), peritoneal dialysis (PD) and supportive care. Transplantation as a treatment requires a medication regime for the lifespan of the transplant. Haemodialysis uses machines and takes three half days of every week, usually at a dialysis centre, and is performed by trained healthcare professionals, although patients can be trained to haemodialyse at home. Peritoneal dialysis treatment can usually be carried out by the patient in their own home or at work. The best option for some people may be not to have dialysis but to receive supportive care from the renal team (www.edren.org, [Accessed] May 2008). Hospital HD costs £35,000/yr, PD £17500/yr and Transplantation £17000 per transplant then £5000 per year in immunisation.

Dialysis Treatment Equipoise

Over the first two years of dialysis there is little or no mortality difference between dialysis options, and once adjusted for co-morbidities, better survival has been shown in PD (Dept of Health 2004a, Murphy 2008, King 1998, Rubin 2000). However, self-care dialysis therapies have been shown to have much lower utilisation rates than unit-based HD. Self-care treatments reach <10% in the United States (Mehrotra et al 2005), and 19% in the United Kingdom (Renal Association 2004). Treatment choice has been studied extensively in the field of Quality of Life (QoL), which has been found to be equitable across HD and PD (Bakewell 2001). With treatment equipoise the foundation for renal patients' treatment decision-making is unique. 'Achieving Excellence in Kidney Care' (Dept of Health 2009), advocates the empowerment of patients to make treatment choices that reflect their personal circumstances. This is supported by renal patient charities:

“Treatment for kidney failure is a means to an end: the choices that you make must, as far as possible, enable you to manage your kidney disease within the context of your life rather than allowing life to revolve around your kidney disease”.

(British Kidney Patients Association, www.britishkidney-pa.co.uk [Accessed] December 2009)

The Renal National Service Framework (NSF) concur, and while they indicate that clinical considerations will determine the treatment options open to the patient, the preferred option should be assessed jointly by the renal

team and the patient (Dept of Health, 2004a). Treatment choice should therefore be made largely by the patient.

There is no typical renal referral or classic renal patient journey. Ideally patients will be referred at the earliest opportunity so further deterioration may be delayed and preparation for the future treatment can be provided. Indeed the policies identified have worked to encourage this. However, in reality some patients may be referred more than 20 years before treatment is ever required because of a known familial disease, such as Polycystic Kidney Disease (PCKD). Other patients will go into acute renal failure and present through the emergency department requiring immediate dialysis to sustain life. Guidelines recommend the education of renal patients should commence twelve months prior to dialysis initiation, to facilitate informed treatment decision-making and the creation of dialysis vascular access (Dept of Health 2005a).

Personal Context

The renal healthcare environment presents a unique context for the patient and the healthcare professional. As an experienced renal nurse working with dialysis patients one is presented with rewards and challenges. The chronic and terminal nature of renal failure necessitates either transplantation or regular dialysis treatment to sustain life. Working with haemodialysis individuals, who required hospital-based provision of treatment thrice weekly, afforded the opportunity to develop well-established patient-professional

relationships. The frequency of patient-professional contact means that in reality, with most patients, there is a degree of informal communication that forms a part of the everyday relationship. It is this element of interest in the patient and their life, and endeavouring to make people feel cared about as well as cared for, in what could otherwise become what feels like a production line process. The patient-professional relationship also provides a unique insight into the individual, the context of their life and their approach to chronic illness. Individuals' differing abilities to cope, adjust and adapt to the demands of treatment, though sometimes well hidden, are laid bare over time.

The impact of dialysis treatment and renal failure symptoms varies greatly from one individual to another, and renal nurses are well placed to determine problems and work to resolve them. However, in a healthcare system founded on achieving clinical targets the quality of patient experience is not recognised often enough. For some individuals the dialysis environment and demands of treatment appear to be overwhelming and all-consuming. Conversely, others appear to be settled and at ease naturally. As a nurse caring for these individuals it raised questions for me about what it was that made such a difference to people's experience. Was it some innate inner calm and if not, was it possible to impact and improve the vast majority of individuals' experience of renal treatment positively?

Training to develop person centred counselling skills, increased my ability to engage empathetically with individuals. My practice shifted away from the traditional problem solving approach and instead centred firmly on patient

centred care. The result was a change in relationship dynamics and my approach to everyday patient education interactions. Education delivery centred on identification of issues, by the patient or myself, and sharing information about potential actions and outcomes. Solutions were focused on the patients needs, in the context of their life and values. Empirically this seemed to result in a much more productive and reciprocal partnership, with greater openness and respect.

With an established interest in the education of patients and the delivery of care, my clinical work grew to encompass the training of patients to perform self-care dialysis either on home haemodialysis or peritoneal dialysis. Whilst satisfying, it simply illustrated for me the stark gulf between patients actively choosing to self-manage and those individuals that never seemed to gain any purchase on their condition.

For those individuals successfully training to self-manage there was no discernible characteristic commonalities, other than their confidence to try. Was this the key element? Do personality traits have the biggest impact? What other influences are at play? This study offered the opportunity to understand better the influences individuals and renal care provision bring to the pre-dialysis experience and how decisions are made about the treatment options.

Theory Phase

Chapter Two:

Literature Review

Chapter Two: Literature Review Chapter

Introduction

The literature review aims to examine evidence about self-management educational interventions and patient decision-making, in long-term conditions. The review will focus on both renal and broader long-term conditions. In conjunction with the nuance and subtleties established from the renal literature, it aims to understand better the potential implications for pre-dialysis educational interventions.

The chapter initially explores chronic disease self-management health policy and the evidence to date. The development of programmes to enhance self-efficacy and the government policy response are then considered. The implications of the renal-specific healthcare policy are examined. The review then progresses to examine pertinent literature and is presented in two sections. Findings are drawn together in the final recommendations and conclusion section.

Development of long-term condition self-management health policy and evidence to date

Choosing a renal replacement therapy is an important decision to take for individuals with chronic renal failure. The current pre-dialysis education situation in the UK is diverse, with local level evolution and a limited evidence basis. A multitude of studies have found education to have a significantly positive effect on patient self-care ability (Lorig 2001, Barlow et al 2002, Singh 2005). However, the rapid development of this material is not yet paralleled by research into its effectiveness. It is a better understanding of this process which will drive the appropriate delivery of information.

Previous studies of renal education interventions focus mainly on nutrition and fluid concordance in patients already established on dialysis (Mason et al 2008). Though this gives insight into the educative processes, it is important to explore the role of theory-based education in the appropriate setting. Self-care studies have predominantly focused on biochemical and financial outcomes leading to a gap in subjective understanding (Goldstein et al 2004, Inaguma et al 2006, Lenz et al 2005), consequently, the format and rationale for pre-dialysis education interventions remains unclear. Several renal studies have identified education as influential in patient treatment decision-making, but fail to describe the relevant educational component content, delivery method or theoretical foundation (Gomez et al 1999, McLaughlin et al 2008, Wuerth et al 2002). There is therefore a need for additional research to elicit individuals' experience of education within the

pre-dialysis journey and to identify components beneficial in their decision-making process.

The management of chronic conditions is a key challenge for the NHS. Greater understanding of the influential educational components and the role of theory-based interventions, in self-care promotion, may lead to improved patient care. Self-efficacy has been identified as an important concept in the development of individuals who are better able to self-care (Lorig 2001, Barlow et al 2005). It is therefore important to understand its origins and utilisation.

Self-Efficacy Concept

The philosophical basis of self-efficacy theory in healthcare is aimed at the development of patient self-confidence and self-belief, enabling them to engage in decision-making and self-management of their disease. It endeavours to moderate behaviour, resulting in improved concordance. Self-efficacy theory was developed by Bandura (1977). Key elements identified as central to self-efficacy development in individuals are:

- Mastery experience; when an individual successfully achieves an undertaking and strengthens their belief in their ability or feelings of self-efficacy.
- Vicarious learning; seeing peers similar to oneself succeed can boost an individual's belief in their own capacity to master an activity.

- Emotional Arousal; individuals' perception and interpretation in response to different emotions and individuals' ability to deal with emotions.
- Verbal persuasion; positive encouragement about one's ability to achieve a goal.

These elements coalesce to enhance individuals' belief in their capacity to cope with the situation in which they find themselves. From this foundation of enhanced self-efficacy it is argued that individuals are better able to make and carry out their informed decisions. Individuals are assisted in developing skills to cope, adjust and adapt to their chronic disease condition.

Development of Programmes to Enhance Self-Efficacy

Bandura and Lorig (1999) were two of the principal investigators involved in the development of the Chronic Disease Self-Management Programme, founded on self-efficacy principles. The intervention was designed to assist individuals with chronic illness in coping with their long-term condition. A randomised controlled trial to evaluate the Chronic Disease Self-Management Programme's impact on health status and utilisation of healthcare resources was conducted by Lorig et al (1999). The programme is highly participative, providing peer support and vicarious learning and runs over six weeks, with two and a half hour weekly sessions. Topics covered include: techniques to cope with psychosocial issues; exercise; medication; communication; nutrition and evaluation of treatment options. Participants receive a course book and relaxation audiotape. Classes are delivered by

either lay leaders or lay and professional leads jointly. Family members are able to attend to support learning and the wider impact of treatment options.

Study participants reported a reduction in health distress, fatigue, disability and social role limitation. Hospitalisation rates were found to decrease. Cost-benefit analysis identified that the cost saving in reduced hospital days, was ten times that of intervention delivery costs (Lorig 1999).

The short-term benefits of self-efficacy-based interventions were established. The longer-term impacts, explored at two years' post-intervention delivery, showed that individuals who participated and completed follow-up had long-term maintenance of self-efficacy, self-management behaviours and improved health status (Lorig et al 2001). The authors surmise that the more self-efficacy is improved, the less health care is utilised. A longer-term effect of reduced healthcare maintenance shows that tertiary prevention improves elements of health status and continues to reduce costs.

Despite no significant deterioration in health status being detected over the two-year period of follow-up period, Lorig (2001) did find an increase in anxiety and depression. One possible explanation is that this is a response shift (Osborne 2006). Response shift identifies a change in an individual's self-evaluation that occurs during the chronic disease self-management programme. The effect of the intervention may alter the individual's internal standards of measurement, resulting in a re-evaluation or a reprioritisation of the individual's values, the consequence being a change to the individual's expectations. In essence the programme may enlighten the individual to the

fact that actually 'things aren't as bad as they thought they were' (a positive response shift) or 'things are much worse than they thought they were' (a negative response shift). This can result in the over-estimation or under-estimation of outcomes through intervention exposure. Hence the classic pre-and post-intervention assessment may be confounded. Osborne (2006) found an alteration in the internal standard of measurement for at least one self-management outcome in 87% of participants. This is an important consideration when designing and deciding on evaluation measures for healthcare educational interventions. Similar findings have been reported with the utilisation of self-efficacy interventions and 12-month follow-ups in the long-term chronic disease population (Barlow et al 2005).

One important area of concern identified is self-selection to participate in the study, thus limiting generalisability of findings due to the likelihood of more motivated chronic disease patients enrolling (Lorig et al 1999). However, when added as a covariant of outcome, it did not affect the results (Lorig et al 1999). The need for longer follow-up of RCTs to confirm that changes are in fact due to course attendance is advocated (Barlow et al 2005). Little is known about individuals who choose not to enrol in interventions (Barlow et al 2005, Lorig 2001). Identification of factors related to non-enrolment in future studies may direct employment of services to diversify or target specific groups.

Self-Efficacy Interventions in the UK

The promotion of self-care was a central element of *The NHS Plan* (Dept of Health, 2000) and focused on the development of patient-centred services. Individuals with long-term conditions such as renal failure were identified as having a role to play in their own care by taking control of their lives (Dept of Health 2005c). The underlying message shifts the emphasis of care from healthcare providers, to individuals' developing the requisite skills to manage their condition better. In doing so, increased quality of life and a reduction in deterioration are postulated. The policy represents a subtle shift in responsibility for health from professionals to the individual (Dept of Health 2001). The emphasis therefore in subsequent policy is on the provision of programmes to develop self-care skills in individuals with chronic disease.

The beneficial effects of the Chronic Disease Self-Management Programme were such that the format was adopted by the Department of Health. The Expert Patient Programme utilises: problem solving; decision-making; resource utilisation; taking action; and the development of effective partnerships with HCPs as the core skills for development and was launched in 2002.

A large two-arm pragmatic randomised control trial, enrolling 629 patients across 28 Strategic Health Authorities, to evaluate the effectiveness and cost-effectiveness of the Expert Patient Programme intervention was conducted (Rogers et al 2007). Participants' self-efficacy and energy levels were reported to have significantly improved, though reduction in health care

utilisation was not significant. However, a small cost reduction was shown indicating that overall the intervention was cost-effective.

It should be noted that the terminology around chronic conditions changed with the policy developments, and the term 'long-term conditions' replaced 'chronic disease'. The long-term condition terminology will be used from this point on.

Government Policy Response to Support Self-Efficacy Interventions

The Expert Patient Programme was piloted in 2002-2004 and rolled out to primary care trusts following the success of the pilot programmes. Publication of the *NHS Improvement Plan: Putting people at the heart of public services* (2004b) coincided with the expansion of the Expert Patient Programme. The policy aimed to provide a high quality personalised service for individuals with long-term conditions. The policy supported patient empowerment and the national utilisation of the Expert Patient Programme. The Department of Health White Paper, *Our health, our care, our say: a new direction for community services*, (2006b) committed to increase Expert Patient Programme capacity to 100,000 by 2012. *Stepping Stones to Success* (DoH 2005b) provided additional backing to the intervention in the form of an implementation, training and support framework for lay-led self-management programmes.

The Department of Health policy document: *Supporting People with Long-term conditions, An NHS and Social Care Model* (2005c) developed a three

tier model to outline the support required by people living with long-term conditions. The model aimed to provide guidance on the most appropriate intervention level for diverse circumstances. (Figure 2.0.0)

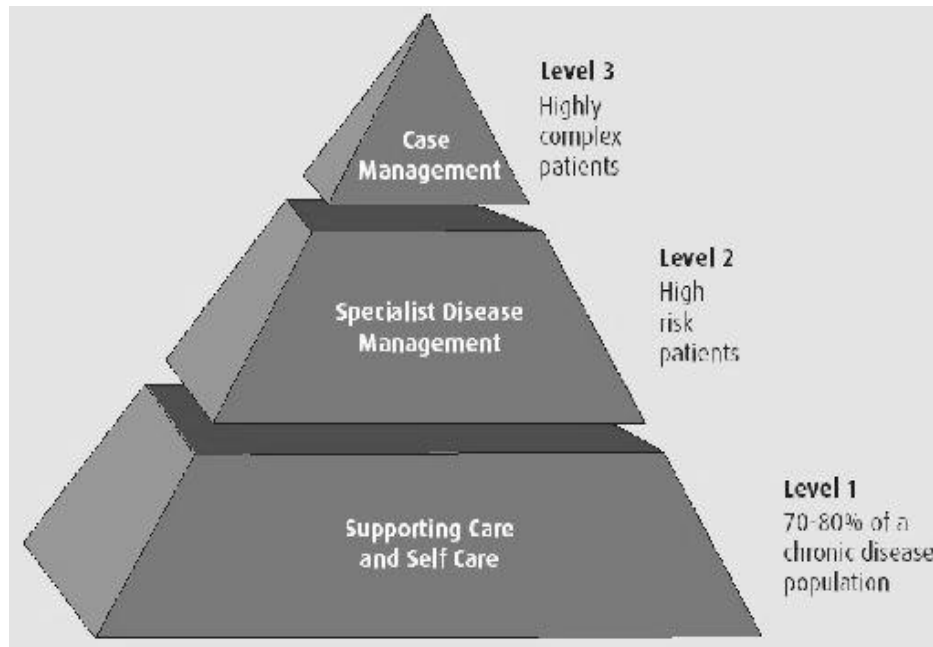


Figure 2.0.0 The NHS and Social Care Long-term Conditions Model

Provision of pre-dialysis educational interventions corresponds with the Level 1 support for self-care stage, applying to 70-80% of the chronic disease population. The requirement of HCPs is:

“Collaboratively helping individuals and their carers to develop the knowledge, skills and confidence to care for themselves and their condition effectively” (Supporting People with Long-term conditions, An NHS and Social Care Model, Department of Health, 2005c, p10).

Renal patients may experience any or all of the levels represented in the Social Care Model during their renal journey progression. However, the vast majority of pre-dialysis renal patients epitomise the Level One tier of the

model. The supportive and self-care ideology underscoring this section of the renal population, currently lacks the theoretical and evidence-based foundation required for the delivery of pre-dialysis patient needs.

Department of Health National Service Frameworks

To identify clear quality requirements in the provision of care, for specific patient groups, the Department of Health developed National Service Frameworks (NSFs). The strategies presented in the NSFs, are the treatments and services that are deemed to work most effectively for individuals, and which are based on the best evidence available at the time. Strategies were developed in collaboration with health services providers, health service users, carers and other experts. The NSFs for Renal: Part One Standard Two identified that:

“Adults approaching end stage renal failure are to receive timely preparation for renal replacement therapy so the complications and progression of their disease are minimised, and their choice of clinically appropriate treatment options is maximised”

(National Service Framework for Renal Services: Part One - Dialysis and transplantation, 2004a p21).

The standard focuses almost exclusively on the medical management of individuals as they progress towards end stage renal failure and gives only superficial consideration to psychological preparation in the form of generic health promotion advice on smoking cessation and increased exercise. Though the framework identifies aims for good practice, it fails to identify

targets or the means of achieving aims in any detail. The markers of good practice identified for Part One: Standard Two include:

- Referral to a multidisciplinary team a year prior to treatment commencement where possible.
- Clinical and psychological preparation.
- Treatment option information provision to facilitate informed choice.
- For acute uraemic emergencies the process needs to be accelerated.

The second part of the framework published a year later, identifies a generic standard for a patient-centred service applicable to all chronic renal failure patients. Part Two: Standard One identifies that:

“Access to information that enables them with their carers to make informed decisions and encourages partnership in decision-making, with an agreed care plan that supports them in managing their condition to achieve the best possible quality of life” (National Service Framework for Renal Services - Part Two: Chronic kidney disease, acute renal failure and end of life care 2005a, p 8).

Markers of good practice are more clearly defined and include:

- Provision of high quality, culturally-appropriate and comprehensive information and education programmes.
- Education programmes tailored to the needs of the individual.
- Individual care plans, regularly audited, evaluated and reviewed.
- Access to a multi-skilled renal team whose members have the appropriate training, experience and skills.

The lack of evidence-based recommendations persists through the second renal NSF, though a shift towards patient-centred care and shared decision-making is founded. There remains no guidance on education components, theoretical foundations or delivery methods.

Long-term condition self-management health policy and evidence to date

The literature informing the development of self-management programmes, and subsequently informing government policy and healthcare frameworks, has grown from research into long-term conditions such as diabetes and arthritis. Whilst there are commonalities between the renal failure population and other long-term conditions, there are also distinct differences. The renal patient journey is unique in the healthcare arena. Individuals are faced with a life-changing treatment decision about options in equipoise. At the point of treatment decision-making individuals may still be functioning normally and the impact of treatment may seem a distant reality. This central decision will radically alter the way in which individuals live their lives, regardless of the treatment option selected. Individuals' life context and values should therefore form the foundation of decision-making. However, this relies on the appropriate provision of information to facilitate informed treatment decision-making. These issues are not reflected in other long-term diseases, with their generally slow and progressive deterioration, where effort is focused on maintenance of optimum health. To understand and identify potential pre-dialysis educational intervention components, their delivery and a theoretical foundation better, a review of the wider chronic disease self-management

and renal literature, as it relates to self-management interventions, will be explored.

Sources of Literature (Search Strategy)

The literature review informing the Theory Phase of the MRC Framework (MRC 2008) focuses on patient education, self-management and self-efficacy in renal and other long-term conditions. The following electronic databases were searched for English language publications from 1980: Medline, Embase, CINAHL, PsychInfo, British Nursing Index, Cochrane Collaboration Trials Register, and Ovid. On-line searches of specialist journals were conducted for American Nephrology Nurses Association, Journal of Advanced Nephrology, American Journal of Kidney Disease, British Medical Journal and Patient Education and Counselling. Hand searches of the British Journal of Renal Medicine and Dialysis & Transplant were also conducted. The use of medical subject headings topics was combined with a key word search to implement a comprehensive search strategy (Table 2.0.1)

| | |
|--|---|
| MeSH Topic terms utilised | [KIDNEY FAILURE] or [KIDNEY DISEASE] OR [CHRONIC RENAL FAILURE] OR [RENAL DIALYSIS] OR [SELF CARE] OR [SELF EFFICACY] OR [EDUCATION] OR [PATIENT EDUCATION] OR [COGNATIVE BEHAVIOURAL THERAPY] |
| Key word search combined with titles and abstract for the MeSH topics | [INTERVENTION] OR [PROGRAM\$] OR [EDUCATION] OR [TEACHING] OR [EMPOWERMENT] OR [SELF EFFICACY] OR [SELF MANAGEMENT] OR [DISEASE MANAGEMENT] OR [PARTICIPANTION] OR [DIALYSIS] OR [RENAL FAILURE] OR [BEHAVIOUR\$] |
| Abbreviations and search symbols | MeSH = medical subject heading \$ = any character |

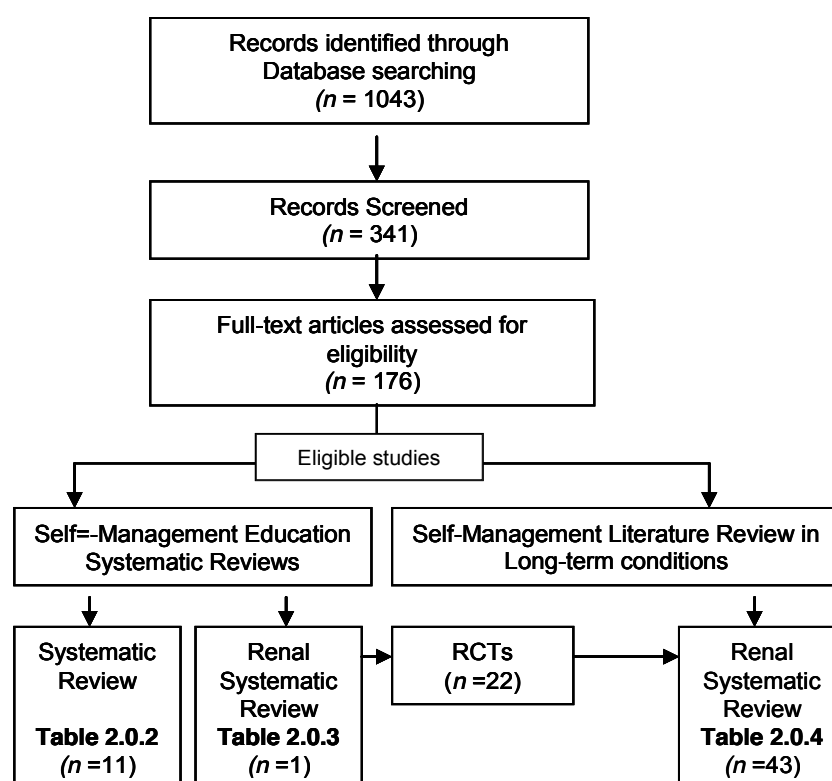
Table 2.0.1 Search Strategy

The screening of the reference list of each article, helped to identify additional relevant publications. The abstracts of all articles were checked to ensure the selection of articles according to three inclusion criteria; the articles were related to adults with somatic chronic illness; the information contained should refer to patient education, self-efficacy or self-management or patient decision-making; the patient education activities described in the articles should be health care professional-led and based within the health care setting. All research methodologies were included.

There are a considerable number of systematic reviews that have covered self-management and the size of this existing evidence indicated that another systematic review of this literature was not appropriate and efficient. Therefore, a review of reviews (Jadad et al 1997, Clarke 2008) was undertaken to explore this literature particularly the findings and discussion related to theoretical foundations of the self-management interventions evaluated in included studies. These reviews are presented in Table 2.0.3.

The only review published on self-management in kidney disease was Mason et al 2008 (Table 2.0.4). These individual studies were reviewed (Table 2.0.5), along with subsequently published studies on the topic and these findings are presented in Table 2.0.4. Search Results are presented in Figure 2.0.2

Figure 2.0.2 Literature Review Search Results



The literature identified from the search informed the development of the studies in the 'Modelling Phase' and was completed in March 2009. The on-going updating of the literature, throughout the Modelling Phase, is discussed in the Methodology Chapter (page 171).

Literature Review Section One: Systematic Reviews of Self-Management Educational Interventions & Decision-Making in Long-Term Conditions

The aims and outcomes of the studies included varied widely depending on the research questions and long-term condition populations studied. Interventions involved components aimed at improving knowledge, self-care, self-efficacy, communication or decision-making and all elements pertinent to the pre-dialysis journey. The intervention formats were utilised in a number of combinations, and this variety influenced the complexity of intervention delivery. A diverse range of measures were utilised including standard clinical assessment measures of blood pressure, pain scores and HbA1c, and questionnaires to measure behaviour, psychological and knowledge outcomes. However, the authors of the systematic reviews are consistently critical of sub-optimal study design, poor study quality, small sample size, short follow-up and evidence of publication bias. The reviews do however identify the type and potential effectiveness of theory use in education delivery. The format and impact of education components and their delivery demonstrates some promising results.

Table 2.0.3 Systematic Reviews of Self-Management Educational Interventions & Decision-Making in Long-Term Conditions.

Table 2.0.3 Summary of Systematic Reviews, Self-Management Educational Interventions & Decision-Making in Long-Term Conditions

| Author Publication Year Title | i) Research Method ii) Studies Included (n) iii) Sample Size iv) Sample Population | Clinical Conditions | Theoretical Frameworks | Intervention Components | Findings | Decision-Making Impact | Limitations |
|---|---|--------------------------|---|---|---|------------------------|---|
| Aujoulet, I. et al 2007 Patient empowerment in theory and practice: Polysemy or cacophony? | i) Systematic Review: Qualitative thematic analysis ii) 55 iii) Not identified iv) Adult | Somatic chronic disease. | Empowerment of patients. Specific empowerment theory not specified. | Therapeutic patient education. Set within the health care context with HCP involvement. | (1) Educational objectives are not disease specific but develop and reinforce psychosocial skills. (2) Empowerment education is based on experiential learning and is patient-centred. (3) The patient-educator relationship needs continuity and joint self-involvement. | Not mentioned | Empowerment in studies was poorly defined and often related to outcomes not empowerment nature. No articulated theory to provide a consistent empowerment definition. |
| Barlow, J. et al | i) Systematic Review | Asthma (n=66) | Several approaches utilise self-efficacy theory. However, | Self-management approaches were groups, individualised | Self-management interventions have a beneficial effect on | Not mentioned | Lack of multi-component description limiting |

| | | | | | | | |
|---|--|--|---|---|---|----------------------|---|
| <p>2002</p> <p>Self-management approaches for people with chronic conditions: a review</p> | <p>ii) 145 articles</p> <p>iii) Not identified</p> <p>iv) Adult</p> | <p>Diabetes (n=18)</p> <p>Arthritis (n=17)</p> <p>Other chronic disease (n=44)</p> | <p>specific studies utilising self-efficacy are not identified.</p> | <p>or both.</p> <p>Booklets, lectures, role play, contracting, buddying, computer, written, manual, problem solving, video and discussion.</p> <p>Bio-psychosocial content.</p> <p>Multi-component.</p> | <p>patients in the short term. Increased participant knowledge, self-efficacy and self-management behaviours are identified in most studies. Several approaches utilise self-efficacy theory.</p> | | <p>understanding of the intervention. Small sample sizes and short follow-up. Heterogeneous: study design, targeted outcomes, measurement tools, the theoretical principles applied to develop and evaluate self-management.</p> <p>Poor component description. Lack of effect size reporting. Lack of cost analysis.</p> |
| <p>Berzins, K. et al</p> <p>2009</p> <p>UK self-care support initiatives for older patients with long-term conditions: a</p> | <p>i) Systematic Review: Narrative Synthesis</p> <p>ii) 18 Studies</p> <p>iii) n=2,965</p> <p>iv) Older Adults</p> | <p>Long-term conditions:</p> <p>Arthritis (n=12)</p> <p>Diabetes (n=2)</p> <p>COPD (n=2)</p> <p>Stroke (n=1)</p> <p>Expert Patient Programme (n=1)</p> | <p>Cognitive behavioural therapy identified in 1 study.</p> | <p>Self-care interventions.</p> <p>Teaching sessions.</p> <p>Group discussion.</p> <p>Written material.</p> <p>A combination of all three elements in group education with</p> | <p>(n=14; 78%) of studies showed significant improvement in one outcome but these were modest.</p> <p>Self-efficacy improved in 5/7, all four interventions using lay leaders improved self-</p> | <p>Not mentioned</p> | <p>Short follow-up period.</p> <p>Heterogeneous outcome measures make effect summary difficult.</p> <p>Lack of rigour in outcome measures.</p> |

| | | | | | | | |
|---|---|---|---------------|--|---|---------------|--|
| review. | | | | HCP delivery. One-to-one exercise session. One-to-one psychologist sessions. | efficacy. Little impact on service use. Modest benefit on physical functioning and illness knowledge. Group sessions are cost effective. | | |
| Chodesh, J. et al 2005 Meta-Analysis: Chronic disease self-management programs for older adults. | i) Meta Analysis: Random Effects ii) 53 RCTs iii) Not identified iv) Adult | Chronic disease: Diabetes Osteoarthritis Hypertension | Not mentioned | 1) Tailored Interventions. 2) Group intervention. 3) Psychological services. 4) Patient feedback. 5) HCP and lay leader education provision. | Self-management interventions significantly reduced HbA1c (-36; 95% Confidence Interval (CI) -0.52 to -0.21) and decrease systolic blood pressure by 5mm Hg (effect size, -0.39 [CI, -0.51 to -0.28]) and decreased systolic blood pressure by 4.3mm Hg (effect size, -0.39 [CI, -0.21 to -0.30]) In pain and osteoarthritis statistical but not | Not mentioned | Heterogeneity of included studies limited interpretation of trials. Lack of patient attributes, disease duration & severity, social support and self-efficacy measures was not accounted for due to poor reporting in trials. Potential publication bias. |

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|--|---|--|---------------|--|---|---------------|---|
| | | | | | <p>clinical significance was established.</p> <p>Effective programme elements cannot be identified from the data; inhibiting specification of elements essential for programme success.</p> | | |
| <p>Cooper, H. et al</p> <p>2001</p> <p>Chronic disease patient education: lessons from meta-analysis.</p> | <p>i) Meta-Analyses: Second Stage Descriptive</p> <p>ii) 12 Meta-analyses</p> <p>iii) Not identified</p> <p>iv) Adult</p> | <p>Diabetes</p> <p>Hypertension</p> <p>Hyperlipidaemia</p> <p>Cardiac Disease</p> <p>Arthritis</p> | Not mentioned | | <p>Need for rigorous research design to explore quantitative and qualitative effects of patient education and education process.</p> <p>Patient education resulted in: Knowledge increase, small psychological effect, physical effect had early moderate effect with decline over time.</p> <p>No correlation found between effect size,</p> | Not mentioned | <p>Short follow-up.</p> <p>Poor description of interventions.</p> <p>Failure to adhere to theoretical models.</p> <p>Poor outcome measures.</p> <p>No review of educational models.</p> <p>No link between theory and practice.</p> |

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|--|--|------|----------------------|---|--|-----------------------|--|
| | | | | | contact frequency and contact time. | | |
| Harrington, J. et al 2004 Improving patients' communication with doctors: a systematic review of intervention studies | i) Systematic Review ii) 25 Studies iii) n=3,526 iv) Adult & 1 paediatric study | | Not mentioned | Written. Face-to-face. Video. | Doctor/Patient communication: Written intervention only 2/10 reported a significant increase. Face-to-face 5/6 reported a significant increase. Video 3/3 reported significant increase. Question asking showed significant increase. Significant improvement in patient recall, perception of control over health, active role preference, compliance, attendance and clinical outcomes. | Not mentioned | Lack of examination of links between intervention success and patient characteristics. No identification of type of intervention for which group of patients. |
| Monninkhof, P. et | i) Systematic | COPD | Bandura (1976) Self- | Self-management | Self-management had | Increased steroid use | Outcome measures |

| | | | | | | | |
|--|--|--|--|--|---|---|--|
| al 2003 Self-management education for patients with obstructive pulmonary disease: a systematic review. | Review ii) 12 Studies iii) n=1,511 iv) Adult | | efficacy Theory recommended in SR's summary but not identified in trials per se. | education modes vary: group, written, individual and action plans. | no effect on: hospital admissions, emergency room visits, sick leave, or lung function. Inconclusive results for: Health Related Quality of Life (HRQoL), COPD symptoms, use of healthcare resources. Rescue medication need reduced and oral steroid courses increased. Positive effect on health outcomes with action plans. | due to consciousness of worsening symptoms and therefore, the help seeking threshold was reduced. | heterogeneity. Insufficient data for making recommendations. The extensive review period of 14 years considers some very recent but also some very dated trials in a rapidly developing field of patient intervention. |
| O'Connor et al 1999 Decision aids for patients facing health treatment or screening decisions: | i) Systematic Review ii) 17 iii) 1,419 iv) Adults | 14 years or older, deciding on screening or treatment options. | Not mentioned | | Decision aids produce: higher knowledge scores (weighted mean difference=19/100, 95% CI 14 to 25); lower decision conflict (weighted mean difference (WMD) =-0.3/5, -0.4 | Not mentioned | Most studies under powered, differing decision drivers, poor evaluation of persistence of choice, poor description of decision aids and comparison |

| | | | | | | | |
|---|--|---|---------------|---|---|---|---|
| systematic review | | | | | <p>to -0.1); more active participation in decision-making (relative risk= 2.27, 95% CI, 1.3 to 4).</p> <p>Complex decision aids were better at reducing decision conflict and marginally improved knowledge more than simple decision aids.</p> | | interventions. |
| <p>O'Connor et al</p> <p>2007</p> <p>Do patient decision aids meet effectiveness criteria of the international patient decision aids (IPDAS) standards</p> | <p>i) Systematic Review & Meta-Analysis</p> <p>ii) 55 Studies</p> <p>iii) 1,454</p> <p>iv) Adult</p> | Individuals using a treatment decision aid. | Not mentioned | <p>Decision aids meeting IPDAS criteria (n=55)</p> <p>Decision quality knowledge scores (n=27)</p> <p>Accurate risk perception (n=12)</p> <p>Value congruence with choice (n=3)</p> | <p>Patient Decision Aids (PtDAs) improve knowledge scores relative to usual care (WMD= 12.2%, 95% CI 11.7 to 18.7).</p> <p>Detailed PtDAs were more effective than simple ones and improved value congruence (WMD = 4.6%, 95% CI 3.0 to 6.2).</p> <p>Perceptions were</p> | <p>PtDAs improve decision quality, decision process, feeling informed and clear about values.</p> | <p>Size of effect varies across studies.</p> <p>Heterogeneity across study outcomes.</p> <p>Inadequate power to detect differences.</p> <p>Variable decision contexts, PtDA elements, comparison of interventions and</p> |

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|--|---|---------------------------------------|---------------|--|---|---|--|
| collaboration? A systematic review and meta-analysis | | | | | <p>improved with PtDAs incorporating probabilities (Relative risk = 1.6, 95% CI =1.4 to 1.9)</p> <p>PtDAs improved process measures relative to usual care (feeling informed WMD = -8.4, 95% CI= -11.9 to -4.8) and (unclear values WMD= -6.3, 95% CI = -10.0 to -2.7).</p> | | evaluation processes. |
| <p>Singh, D. et al</p> <p>2005</p> <p>Transforming chronic care: a systematic review of the evidence.</p> | <p>i) Systematic Review</p> <p>ii) 560 Studies</p> <p>iii) Not identified</p> <p>iv) Adult</p> <p><i>(Sub-Review: Interventions Targeting Patient:</i></p> <p><i>ii) 32 Studies</i></p> <p><i>iii) Not identified</i></p> | Involving patients in decision-making | Not mentioned | | <p>Involving patients in decision-making may improve care satisfaction.</p> <p>Varying levels of desire for decision-making.</p> <p>No ideal theoretical approach identified.</p> | No specific decision-making theory or methodology identified. | Little evidence of impact on outcomes. |

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|--|--|------------------------|---------------|--|--|---------------|--|
| | <i>iv) Adult</i> | | | | | | |
| | <i>(Sub-Review:</i> <i>Accessible</i> <i>Information:</i> <i>ii) 70 Studies</i> <i>iii) Not identified</i> <i>iv) Adult</i> | Accessible Information | Not mentioned | Written information. Individual education sessions. Group education sessions. Lay educators. Technology. | Written information improves knowledge but not bio-psychosocial outcomes. Group sessions improve knowledge, satisfaction, medication use but less so symptom and clinical outcomes. Lay educators improve access to care and behaviour change. Technology no consistent evidence. | Not mentioned | |

| | | | | | | | |
|---|--|---|---|---|--|---------------|--|
| | <p><i>(Sub-Review: Self-Management Education:</i></p> <p><i>ii) 52 Studies</i></p> <p><i>iii) Not identified</i></p> <p><i>iv) Adult</i></p> | Self-management Education | Not mentioned | Education programmes. | <p>Education programmes can help patients manage their conditions.</p> <p>Fewer symptoms and less GP and hospital visits associated.</p> | Not mentioned | Not enough research to identify programme types that are effective. |
| <p>Warsi, A. et al</p> <p>2004</p> <p>Self-management education programs in chronic disease.</p> | <p>i) Systematic Review and Methodological Critique</p> <p>ii) 71 studies</p> <p>iii) n=14,588</p> <p>iv) Adult</p> | <p>Arthritis (n=24)</p> <p>Asthma (n=16)</p> <p>Diabetes (n=16)</p> <p>Hypertension (n=10)</p> <p>Miscellaneous (n=5)</p> | <p>Social Cognitive Theory (n=21)</p> <p>Cognitive Behavioural Therapy (n=6)</p> <p>Reality therapy (n=1)</p> <p>Behavioural Feedback (n=1)</p> <p>Problem Orientated Participatory Education (n=1)</p> <p>No Theory (n=47)</p> | Programme duration, number of educational sessions and format showed no significant difference to the improvement effect. | <p>Diabetics had a significant reduction in HbA1c (summary effect size, 0.45; CI95%, 0.17-0.74) and systolic blood (summary effect size, 0.20; CI 95%, 0.01-0.39) pressure.</p> <p>Asthmatics had significantly fewer attacks (log rate ratio, 0.59; CI 95% 0.35-0.83).</p> <p>Arthritis showed a small positive, but none significant, effect.</p> <p>Behavioural science</p> | Not mentioned | <p>Evidence of publication bias.</p> <p>Lack of standardised methodology in self-management education.</p> <p>Suboptimal trial design.</p> |

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| | | | | | models were not significantly associated with improvement. | | |
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Theoretical Frameworks

The application of self-efficacy theory was identified in half (n=9) of the self-care studies reviewed by Berzin's et al (2009). Self-efficacy is highlighted as a key predictor of behaviour change and positive self-care activity. Nonetheless, the failure of studies to describe content and theoretical foundations sufficiently inhibits a thorough understanding of interventions.

Barlow et al (2002) reviewed self-management approaches in long-term conditions and found most to be multi-component approaches. Barlow et al highlight that multi-component interventions are generally designed to increase self-management, within the context of an individual's chronic condition. She argues that individuals will select the technique they feel fulfils their needs. The review identifies the use of social, cognitive and behavioural theories, and for several approaches self-efficacy theory specifically, was advantageous.

These theoretical approaches are identified as increasing knowledge, self-management behaviours, self-efficacy and are of benefit to participants in comparison to standard care. Effect was established as comparable with cognitive behavioural interventions and most self-management interventions are reported as being group-based. The financial efficacy of group education is an important consideration in intervention delivery and sustainability.

Aujoulet et al's (2007) review, established that self-efficacy concepts (Bandura 1977) were frequently associated with empowerment interventions.

Self-efficacy was identified in the studies in a diverse array of associations: as a goal of empowerment (n=3); an indicator of empowerment (n=9); and as a pre-disposing factor for empowerment (n=6). Interventions aimed at enhancing self-efficacy are therefore recommended strategies for patient education to improve self-management effectiveness.

Methods of education delivery included experiential learning and were patient-centred. Aujoulet et al, intimate that underlying self-efficacy enhancement frameworks are at work, and the provision of vicarious learning and mastery opportunities are provided by the group environment. Contrary to Aujoulet et al's findings, Monninkhof et al's (2003) review found that action plans produced the most positive effect on health outcomes. The authors' recommend the use of Bandura's Self-efficacy theory (1976), as the foundation for interventions.

However, not all reviews identify unambiguous connections between theoretical foundations and study outcomes. A review by Chodesh et al (2005) found that despite extensive quantitative and qualitative analysis of studies, the effective theoretical foundations of self-management programmes could not be identified. However, the potential for self-management programmes to improve individuals' concordance with medication regimes was postulated as a potential explanation for significantly improved; HbA1c (-36; 95% Confidence Interval (CI) -0.52 to -0.21), systolic blood pressure (summary effect size, 0.20; CI 95%, 0.01-0.39) and significantly fewer asthmatics attacks (log rate ratio, 0.59; CI 95% 0.35-0.83). The potential impact of increased medication concordance over the lifetime

of an individual's long-term condition journey has implications, in terms of health-related quality of life and healthcare costs.

Further issues with the utilisation of theoretical foundations in education delivery are identified. Cooper et al's (2001) review, of meta-analyses of chronic disease patient education, postulates that a lack of understanding of the self-efficacy concept is reflected by the failure of trials to identify theoretical models of behaviour. This raises the feasibility issue of introducing self-efficacy interventions into clinical practice and the associated need to communicate self-efficacy theory to the wider multidisciplinary clinicians involved in patient care. These issues notwithstanding, interventions utilising enhanced education methods or cognitive behavioural approaches, were found to be more effective than psychosocial and didactic formats. Those studies that identified a theoretical basis were consistently found to be associated with a larger effect size.

Warsi et al (2004) reviewed self-management education programmes in long-term conditions reporting on self-management outcomes. The authors found the failure of studies to report underlying theoretical foundations and outcomes, such as patient attributes and self-efficacy scores, limited the evaluation of factors contributing to study success. Interestingly, better outcomes were not found to be associated with those studies identifying a specific behavioural framework.

Four of the reviews identify the theoretical foundations of intervention studies. They identify self-efficacy and empowerment theories as beneficial to, and impacting upon outcomes, and as components of the interventions delivered

(Aujoulet et al 2007, Barlow et al 2002, Berzins et al 2009, and Monninkhof et al 2003). No other theoretical approaches were identified. One criticism levelled by most reviews is the lack, if not complete absence, of theoretical foundation identification in intervention studies. The heterogeneous reviews present theoretical foundations as a secondary consideration, with the main focus on intervention components. The result is the inability to distinguish between the impact resulting from theory, educational components or a combination of both. In reality it is likely that these elements as a whole equal more than the sum of their parts, and are therefore not mutually exclusive.

Education Component

Intervention components varied considerably in terms of complexity and delivery methods, in addressing long-term condition, knowledge and behaviour. Most interventions were healthcare professional-led, though one review identifies the use of lay leads (Barlow et al 2002). Educational components included- written information, peer support, lectures, and problem solving (Barlow et al 2002). However, individual component content is poorly described and most reviews reporting intervention components identify a combination of some, or all of the delivery methods. Outcome measures varied widely.

Group sessions (n=5), 1 to 1 (n=5) and written materials (n=8) are the most frequently and consistently reported beneficial intervention components

employed in the studies reviewed. Berzins et al (2009) found that most education delivery was in small groups and was combined with problem solving, discussion and goal setting for individuals. Berzins et al, go on to identify more specifically the self-efficacy components of role modelling, mastery experience, verbal persuasion, and how reinterpretation of physiological state was applied to education and self-care support programmes. These elements are important for pre-dialysis individuals who are in a state of declining health requiring on-going physical and psychological adjustment. Aujoulet et al (2007), like Berzins, is one of the few reviews to provide greater detail on the format of group session. She details group sessions in the studies reviewed (n=8) as involving: topic explanation, group discussion, a practical exercise, self-reflection and goal setting. Thus the core foundations of self-efficacy theory are incorporated. Barlow et al (2002) concurs with these findings and identifies group sessions as being as effective as tailored one-to-one sessions. Consideration of these findings will influence pre-dialysis education delivery. However, it is worth noting, that many group interventions in the review include individualised elements such as counselling. The efficacy of face-to-face interventions is supported by Warsi's (2004) review.

Written material supported most intervention studies described in Berzin et al's (2009) review. Eleven interventions were supported with written materials and though some utilise established resources, such as 'The Arthritis Handbook' (n=3) or accessibility tested material (n=1), the remainder fail to identify the source or quality of written material. Arthritis literature dominated Barlow et al's review and particular reference is made to use of a manual in

the Arthritis Self-Management Programme developed by Lorig et al (1999). The manual was found to impact knowledge, self-management behaviours and self-efficacy positively. The limited identification of written material hampers identification of appropriate content and format for delivery. However, the need for written information to support intervention delivery is established.

Lay and professional leaders were found to be equally effective in intervention delivery (Barlow et al 2002). Berzin et al (2009) concur and identify equity of effect when professional and lay leaders delivered interventions. Singh (2005) additionally identifies participants improved access to care and behaviour change with lay leaders. Barlow et al (2002) go on to highlight the greater cost effectiveness of lay lead interventions. The potential for lay leaders to increase self-efficacy behaviour through positive role modelling and provide strongly homogeneous, vicarious learning therefore exists, and posits well with the use of self-efficacy theory to guide pre-dialysis intervention delivery.

Berzins et al explored the timing of intervention delivery. With sessions lasting on average two hours and courses being run over several weeks, the associated cost and travel negatively impacts on the uptake and completion of interventions. It could be argued that these issues would be further compounded in a pre-dialysis renal cohort. Pre-dialysis patients are mainly older individuals and some will potentially be coping with a fluctuating health status and this is of particular relevance in a long-term condition where health status is declining. However, even with multi-faceted interventions, with

varying delivery methods and timing, Cooper et al's (2001) review failed to detect any beneficial impact associated with particular frequency or total contact time. Thus a balance needs to be achieved, between sufficient education delivery and feasibility for participant uptake and completion.

Self-management interventions aimed at enhancing self-efficacy, introduced new ideas aimed at the promotion of behaviour change (Barlow et al 2002). It is argued that through successful behaviour change, the confidence to self-manage develops (Bandura 1977). These programmes can therefore be seen to lay the foundation upon which self-efficacy can develop and as such this is a progressive and on-going process. The short-term follow-up periods reported across the systematic reviews consistently fail to identify the true longer-term impact. Self-efficacy appears to be a slow burn intervention with successful experience building to further develop and enhance self-efficacy.

The notion of continuous development throughout an individual's illness journey is to some degree dependent on the understanding of, and continued practice to enhance, individuals' self-efficacy by HCP's. However, with self-efficacy theory comprehension and its conscious application previously identified as lacking in professional education delivery this is questionable. The potential for individuals to develop self-efficacious behaviours and then become frustrated if these are denied, as their illness journey progresses and HCP change, is a concern. Even with enhanced self-efficacy it takes a particularly confident individual to challenge healthcare delivery in a service providing their care.

Decision-Making

A central function of pre-dialysis education is to increase individuals' understanding of renal failure and the treatment options available, so that individuals can make an informed treatment choice. Decision-making is therefore a key element of the participants' pre-dialysis journey.

Decision aids are described as an adjunct intervention designed to provide information about outcomes associated with different treatment options, for individuals who need to make deliberate and specific choices (O'Connor et al 1999). The decision aids reviewed by O'Connor et al, comprise a diverse range of decision-making situations. The decision aid objectives focus on increasing knowledge; patient satisfaction, participation in decision-making and the reduction of decision conflict are outcomes of interest in the renal treatment decision-making arena. A common foundation for all the decision aids reviewed was the inclusion of information on the clinical problem, options and outcomes. The most consistent finding about decision aids was the significant increase in knowledge to a level at which informed treatment decision-making could occur (weighted mean difference=19/100, 95% CI 14 to 25). Individuals were found to be more comfortable with their choice (weighted mean difference (WMD) =-0.3/5, -0.4 to -0.1), and as a result, more likely to follow-through with their decision. Decision aids increase active participation in decision-making (relative risk= 2.27, 95% CI, 1.3 to 4) and were found to have the greatest effect when combined with coaching. Decision aids are not directed at changing peoples' decisions. Rather they aim to enable individuals to make the best decision for the context of their

life, based on their own values. The review found decision aids to be better than the usual care for improving individuals' knowledge, reducing decision conflict and increasing participation in decision-making.

Development of International Patient Decision Aid Standards (O'Connor et al 2007) has facilitated the evaluation of decision aids to meet effectiveness criteria (O'Connor et al 2007). A greater emphasis is placed on patient values in the evaluation of good decision-making. Indeed decision quality is founded on patients making decisions most in-line with their values. Decision aids were found to carry the same benefits identified in the earlier review. Furthermore, individuals utilising complex decision aids were more likely to have an accurate risk perception.

Despite the on-going necessity for decision-making throughout individuals' long-term condition journey, the self-management intervention literature makes little reference to the process. Indeed there is a complete absence of decision-making theory, and no associations have been made between self-management theory and decision-making.

Aujoulet et al (2007) provides the most comprehensive insight into the decision-making process. Eight of the 55 studies reviewed express the importance of the decision-making process on the outcomes of empowerment. She describes the multitude of influences that have a bearing upon the decision-making process, and these include the psychosocial impacts of living with long-term conditions and the potential for discrepancy between individuals' goals and HCPs' expectations. What is explained is the need for sufficient time in decision-making, to facilitate individuals'

consideration of options, so they can make their own decisions, and where necessary, negotiate treatment options.

However, Aujoulet singles out the findings of one study by (Anderson 1991, cited Aujoulet et al 2007). The study identifies the active abdication of treatment decision-making to HCPs', and cautions that this too is an empowered process if it achieves the individual's goal. This summation is supported by Singh (2005), who identifies that some individuals will want to be more involved than others in the decision-making process. Shared decision-making is identified by Aujoulet et al (2007) as a frequently anticipated outcome of studies. However, the systematic review fails to exemplify any reference to decision-making theory or foundations.

The incorporation of treatment-related decision-making as an effective element of a computer-based educational intervention, in osteoarthritis, was identified by Chodesh et al (2005), in a single study out of the 53 studies systematically reviewed. The result was increased use of appropriate medication, and was identified as an important impact. However, the lack of any decision-making theory or intervention details limits the inferences to be drawn.

The lack of decision-making reference across the systematic reviews is reflected by Singh (2005). She reviewed interventions targeted specifically at involving people in decision-making. Despite her comprehensive review the findings remain limited. Singh concludes that satisfaction with care may improve when individuals, with long-term conditions, are involved in decision-making. She fails to discern any theoretical foundations or evidence to

suggest the most effective or appropriate decision-making approach. Furthermore, the impact of decision-making on clinical outcomes and healthcare resource use is lacking.

With decision-making so infrequently and poorly reported, it is difficult to draw any robust conclusions from the systematic reviews. However, more subtle inferences may be derived. The positive impact upon appropriate medication utilisation found in long-term conditions (Chodesh et al 2005), corroborates the postulation that improved self-efficacy results in improved medication concordance and has long-term benefits. The concept of a relationship, between self-efficacy and decision-making, starts to be uncovered. With empowerment and self-efficacy inter-twined throughout the literature (Aujoulet et al 2007, Paterson et al 2001), the potential association with, and the impact of decision-making could be argued to be a key to educational intervention development.

Outcomes

Individuals need to understand dialysis treatment choices, if they are to actively engage in informed decision-making. A fundamental element of pre-dialysis care is to provide education, which patients are able to comprehend, and therefore can effectively utilise to aid treatment decision-making.

A synthesis of resulting effect across the reviews of intervention components and theory-based education for people with long-term conditions, suggests that a behavioural science theoretical foundation has a positive impact on

knowledge, self-efficacy and self-management behaviours. The reviews report clinical (n=7) and behavioural (n=9) outcome measures. Mixed results were found for changes in healthcare service use, but more appropriate use of services is postulated. However, short-term follow-up limits the understanding of potentially positive longer-term impact.

Objective clinical improvements were shown for HbA1c (-36; 95% CI -0.52 to -0.21) (Chodesh et al 2005) and asthmatics suffered significantly fewer attacks (log rate ratio, 0.59; CI 95% 0.35-0.83) (Warsi et al 2004) in the diabetic and respiratory disease populations studied. For the hypertensive populations studied, the clinically subjective outcomes identified a reduction in systolic blood pressure by 5mm Hg (effect size, -0.39 [CI, -0.51 to -0.28]) and diastolic pressure by 4.3mm Hg (effect size, -0.39 [CI, -0.21 to -0.30]) (Chodesh 2005)

Anxiety and depression were not assessed in any of the included trials. Health related quality of life was reported in one review (Monninkhof et al 2003) with no between group differences, or within group differences. This may indicate the inappropriate nature of quality of life measures; in the evaluation of long-term condition educational interventions or that the wrong measure was used.

O'Connor et al (1999, 2008) reported that decision aid use, improved patient decision quality, enhanced decision processes and patients feeling informed and clear about their values. Cognitive behavioural outcomes reported in the reviews (n=9) support the decision aid review findings. Reviews found an increase in self-efficacy behaviour, patients were more actively involved in

decision-making and individuals' perceived an increased control of their health status.

Limitations

A lot of uncertainty remains about the role of the evidence presented in the systematic reviews. The limitations of the studies cited throughout the reviews are: small sample size; short follow-up; lack of theoretical foundation description; lack of component/intervention detail; lack of cost-effectiveness reporting; evidence of publication bias and sub-optimal trial design. The validity and reliability of the systematic reviews based on scant or indeed inferior trials, means findings and recommendations must be considered with caution.

Recommendations

The synthesis and integration of systematic review findings reveals some important considerations in the development and delivery of pre-dialysis educational interventions. Multi-component interventions incorporating written, individual and group education delivery can facilitate the tailoring of education to individual needs, and were found to improve a diverse range of patient outcomes including; knowledge, self-efficacy, HbA1c, systolic and diastolic blood pressure. Group education sessions provided similar benefits and were cost-effective. Behavioural theory foundations work in combination with educational components to improve patient knowledge, self-efficacy,

self-management and clinical outcome measures. Incorporation of decision-making aids into educational interventions improves the quality of patients' decision-making processes and reduces decision conflict.

Literature Review Section Two: Randomised control trials of Renal Educational Interventions and the broader Renal Literature concerning Educational and Treatment Decision-Making in Individuals with Kidney Failure.

Introduction

The only comprehensive systematic review kidney disease educational interventions (Mason et al 2008), identifies twenty-two studies fitting the rigorous inclusion criteria. The review precluded kidney transplant recipients and focused on; early (CKD stages 1-3), pre-dialysis (CKD Stages 4-5) and dialysis patients (CKD stage 5). Mason et al (2008), report that due to the lack of heterogeneity in the study results, meta-analysis was not possible (Table 2.0.4). Eighteen of the 22 studies included focus on improving diet and/or fluid concordance. All studies were multi-component and the identified outcomes considered clinical, behavioural, psychological and knowledge measures. The extensive, comprehensive and clearly identified search strategy, selection criteria, data extraction and analysis add greatly to the validity of this systematic review.

These individual studies from Mason et al review have been reviewed (Table 2.0.5), along with subsequently published, qualitative and quantitative, studies on the topic and these findings are presented in Table 2.0.5.

Table 2.0.4 Summary of Systematic Review Findings about Renal Disease Self-Management

| Author Publication Year Title | i) Research Method ii) Studies included (n) iii) Sample Size iv) Population | Clinical Conditions | Theoretical Framework | Intervention Components | Findings | Decision-Making Impact | Limitations |
|--|--|---|---|---|--|--------------------------------------|--|
| Mason, J. et al 2008 Educational Interventions in Kidney Disease Care: A Systematic Review of Randomized Trials | i) Systematic Review ii) 22 Studies iii) 1,967 iv) Adult | CKD stages: 1-3, Early (n=0) 4-5, Pre-dialysis (n=5) 5, On dialysis (n=17) | No theory (n=6), Social Learning theory (n=3), Cognitive Behavioural Theory (n=2), Collaborative Role Learning (n=2) <i>The following theories are reported on one occasion (n=1):</i> Self-efficacy Theory, Empowerment, Behavioural orientation, Behaviour modification, Oral cultural traditions, Transaction theory, Trans-theoretical motivational interviewing and health care model, Rehabilitation model, Orem's theory of self-care. | Individual education. Group education. All hospital based. One study peer lead, others HCP lead. Session range 15mins-4hrs. Pre-dialysis group education should be researched as it is more cost effective, provides peer support and shared experience. | 18 studies (82%) report significant results for one outcome: behavioural, psychological, clinical or knowledge. <i>Short-term follow-up:</i> Written material and a single patient centred group session significantly improved self-care dialysis knowledge ($P<0.02$), self-efficacy ($P=0.02$), and self-care dialysis selection (adjusted OR 10.2, 95%CI 2.0 to 50.3). <i>Long-term follow-up (20 years):</i> Session extended and phone follow-up added to original format. Improved long term knowledge retention, delayed onset of dialysis and significantly increased survival rates of 2.25 years (Relative Risk 1.35, 95% CI 1.02 to 1.8). A framework is required to improve design, delivery and evaluation of interventions. | Increased self-care decision-making. | Heterogeneity of studies prevents meta-analysis. Sub-optimal RCT methodology. Poor reporting. Small sample size. High dropout rates. Inconsistent intervention delivery. |

Table 2.0.5 Summary of Literature Review Findings: Educational Interventions and Renal Disease Self-Management

| Author Publication Year Title | i) Study Design ii) Sample Size iii) Sample Population | Population | Outcome Measures | Theoretical Framework | Intervention Components | Findings | Decision-Making Impact | Limitations & Recommendations |
|--|--|-----------------------------|--|-----------------------|---|--|------------------------|---|
| Ashurst, I. & Dobbie, H 2003 A randomised controlled trial of an educational intervention to improve phosphate levels in haemodialysis patients | i) RCT ii) 58 iii) Adult | Haemodialysis | Diet concordance | Not identified | A single 40 minutes, hospital based, dietician delivered, one-to-one session including: education on phosphate & calcium control, a patient guide, medication & results review, charts for self-monitoring. | At 3 months: Increased diet concordance and significant decrease in mean phosphate (mean difference, -0.36mmol; 95% CI, -0.54 to -0.16). Changes in mean calcium & calcium phosphate product ($P=NS$). | | Limitation: Poor reporting Limited follow-up. Recommendation: Behavioural strategies have an important role to play in the treatment of renal patients. |
| Binik et al 1993 | i) RCT ii) 179 iii) Adult | CKD Stage 4-5, pre-dialysis | Time to dialysis Kidney Disease Questionnaire assessing knowledge | Not reported | One-to-one 90-minute session with trained research assistant including: slide lecture, booklet psychosocial | Increased average time to dialysis initiation ($P=0.05$) Increased knowledge of kidney disease | N/A | Limitation: Poor reporting Recommendation: Enhanced education can |

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| Live and Learn: Patient education delays the need to initiate renal replacement therapy in end- stage renal disease | | | levels | | support. | ($P<0.001$) | | extend time to dialysis and reduce costs. |
| Cummings K. 1981 Intervention strategies to improve compliance with medical regimens by ambulatory haemodialysis patients | i) RCT ii) 116 iii) Adults | Haemodialysis | Diet and fluid concordance with potassium and interdialytic weight gains. Health beliefs measure. | Behaviour modification & health beliefs model | Weekly for 6 weeks, hospital based one- to-one sessions including: Behaviour contracting, family support, advice and praise. | At 6 weeks follow-up: Increased diet concordance ($P=0.05$) Increased fluid concordance ($P=0.05$) Changes in health belief and diet & fluid changes at 3 months NS Health beliefs were not predictive of concordance | | Limitation: poor reporting. Recommendation: intervention results tapered off to pre-intervention levels once discontinued, thus continuous follow- up is needed with patients. Future research must focus on the mechanisms through which behaviour works and can maintain change. |
| Cummings K. | i) RCT ii) 116 | Haemodialysis | Diet and fluid concordance with potassium and interdialytic weight | Behaviour modification & health beliefs model | Weekly for 6 weeks, hospital based one- to-one sessions including: Behaviour | At 6 weeks follow-up: Increased diet concordance ($P=0.05$) | | Limitation: poor reporting. Recommendation: |

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| 1981 Intervention strategies to improve compliance with medical regimens by ambulatory haemodialysis patients | iii) Adults | | gains. Health beliefs measure. | | contracting, family support, advice and praise. | Increased fluid concordance ($P=0.05$) Changes in health belief and diet & fluid changes at 3 months NS Health beliefs were not predictive of concordance | | intervention results tapered off to pre-intervention levels once discontinued, thus continuous follow-up is needed with patients. Future research must focus on the mechanisms through which behaviour works and can maintain change. |
| Curtin R & Mapes DL 2001 Health Care Management Strategies of Long-Term Dialysis Survivors | i) Exploratory Descriptive Study: Semi-structured interviews. ii) Interviews (n=18) iii) Adult | Dialysis patients on treatment for 15 years or more. Male (n=10) Female (n=8) | Self-management strategies for long-term dialysis survivors. | | | Survivors displayed: Relationships with HCP; Managing healthcare systems; impression management; selective symptom reporting, proposal of treatment by the patient; active self-advocacy and independent adoption of treatment. | | Small sample size, non-generalizable. <i>Recommendation: Development of interventions for active partnership in care to successfully manage renal disease.</i> |
| Diemling A, et al | i) RCT ii) 3 | Haemodialysis | Diet concordance, time within phosphorous range, peer assessed | Social Learning Theory | One-to-one with nurse educator including: slides/tape, | At 3 months increased: diet concordance phosphorous ($P=NS$), | | Small numbers, poor reporting, short follow-up. |

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| 1984 | iii) Adults | | knowledge test. | | education session, goal monitoring contract. | knowledge improved. | | |
| Effect of an algorithm and patient information on serum phosphorus levels | | | | | | | | |
| Devins et al 2000 | i) RCT ii) 47 iii) Adult | CKD Stage 4, pre-dialysis | Kidney Disease Questionnaire at: Baseline, 18m, 30m, 42m & 54m | Not reported | One-to-one 90 minute session with trained research assistant including: slide lecture, booklet psychosocial support (the same as Binik 1993) | | | |
| Long-term knowledge retention following pre-dialysis psychoeducational intervention | | | | | | | | |
| Devins et al 2003 | i) RCT follow-up at 18 months ii) 297 iii) Adult | CKD Stage 5, dialysis patients | Time to Dialysis Kidney Disease Questionnaire to assess knowledge. Anxiety & Depression Self rated social | Not reported | Hospitals based individual 90 minute session with a social worker including: slide lecture, booklet, psychosocial support and telephone | At 18 months: Increased time to dialysis ($P<0.001$) Increased knowledge of kidney disease ($P<0.001$) Increased reported | N/A | Limitation: Target sample somewhat short. No renal specific questionnaire. Some missing data. Recommendation: Pre-dialysis |
| Pre-dialysis psychoeduca- | | | | | | | | |

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| tional intervention and coping styles influence time to dialysis in chronic kidney disease | | | support measure | | support calls. | depression ($P=NS$) Increased reported anxiety ($P=NS$) Increased social support ($P=NS$) | | psycho-educational intervention extends time to dialysis. Supportive follow-up is important for patients who cope by avoiding threat related information. |
| Devins G, Mendelssohn D, Barre P, Taub K, Binik Y. 2005 Pre-dialysis psycho-educational intervention extends survival in CKD: A 20-year follow-up | i) RCT: Follow-up ii) $n=335$ iii) Adult | CKD participants from the original trial. | Difference in survival for early and late referral to nephrology. Survival post dialysis commencement. | | Psycho-educational intervention. One-to-one session with a HCP including: kidney disease and normal function, diet, medication, treatment options and written information. | Mean survival was 2.25 years longer in the intervention group (chi-square-change [1] = 3.75; $P=0.053$; hazard ratio, 1.32; 95% CI, 1.0 to 1.74) and 8 months longer following initiation of dialysis therapy (chi-square-change [1] = 4.39; $P=0.036$; hazard ratio, 1.35; 95% CI, 1.02 to 1.775). | | Limitations: The study is underpowered as survival was not a primary outcome. Recommendation: Psycho-educational interventions are safe and achieve a meaningful delay in treatment commencement. Future research should delineate the mechanisms. |
| Ford, J et al 2004 | i) RCT ii) 96 iii) Adult | Haemodialysis | Diet concordance Knowledge | Not identified | Six, 20-30 minute, hospital based, one-to-one dietician delivered sessions over 6 months. | At 6 months: Increased knowledge ($P=0.02$); Increased diet concordance with decreased phosphate | | Limitation: Short follow-up Recommendation: Extra education monthly may be |

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| The effect of diet education on the laboratory values and knowledge of haemodialysis patients with hyper-phosphatemia | | | | | | product ($P=0.001$) & calcium-phosphate product ($P=0.001$); change in parathyroid hormone ($P=NS$) | | beneficial in reducing hyper-phosphatemia |
| Goldstein et al 2004 Multidisciplinary pre-dialysis care and morbidity and mortality of patients on dialysis. | i) Prospective Cohort Study ii) 271 iii) Adult | Pre-dialysis patients (n=184) Progressive Renal Disease Clinic (n=61) Usual Care (n=26) | Biochemistry Morbidity Mortality | | Multidisciplinary clinic: nephrologist, nurse educator, dietitian, pharmacist and social worker and a trained peer support volunteer. | In the intervention group: Serum albumin was higher at dialysis commencement (3.7g/dL [37g/L] versus 3.3 g/dL, $P < 0.01$) non-significant trend towards lower serum phosphate and higher Hb. Significantly reduced hospitalisation at 1 year (7.0 versus 69.7 d/patient/year; $P < 0.01$) and lower mortality (2% versus 23%; $P < 0.01$). | | Limitation: Potential for case bias mix in prospective design. Small sample size. Poor description of intervention. Lack of theoretical intervention foundation identification. Recommendation: multidisciplinary intervention to deliver pre-dialysis care. |
| Gomez et al 1999 | i) Multi-Centre Controlled | Pre-dialysis Centres (n=14) | Pre and post information evaluation of kidney disease knowledge | | Standard Information Pack: delivered by a HCP over 2 | Intervention group: Significant increase in knowledge of treatment option (HD | | Limitations: Non-validated questionnaires. Lack of theoretical |

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|---|--|---|---|--|--|--|---------------|--|
| Validity of standard information protocol provided to end-stage renal disease patients and its effect on treatment selection. | Trial ii) 314 iii) Adult | | and treatment options available. Questionnaires: 1)Pre-information 2)Post-information 3)Treatment Start | | appointments, treatment option flip chart, renal replacement guidebook, video, and handbook. | pre-informed knowledge 2.56 versus post-informed knowledge 4.31 $P<0.0001$ (PD pre-informed knowledge 1.91 versus post-informed knowledge 4.04 $P<0.0069$). PD was least well known. | | foundation for education delivery. Recommendations: Use of a standard information pack and specifically the guide to treatment options. Simple clear PD diagrams. |
| Harris, M. et al 2005 Printed patient education interventions to facilitate shared management in chronic disease: a literature review. | i) Literature Review ii) 7 studies iii) n=1,101 iv) Adult | Inflammatory Bowel Disease (n=3) Arthritis (n=2) Asthma (n=1) Diabetes (n=1) | Not mentioned | | Controlled trials of printed patient materials in chronic disease. | Statistically significant change was found for a few measures. Knowledge improved in three studies (2 inflammatory bowel, 1 arthritis). | Not mentioned | Poor study design. Studies failed to name primary outcomes, were short with follow-up of less than 6m, and did not include process evaluation. Behaviour change rational was lacking. Evidence of publication bias. |
| Iles-Smith H 2005 | i)Semi-Structured Interviews | Pre-dialysis | Subjective perceptions, pre-dialysis experience and expectations of | | | Provision, quantity, timing and interpretation of information resulted in | | Small sample size and reduced ethnic diversity. Convenience |

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| Perceptions and experiences of pre-dialysis care. | ii) 10 iii) Adult | | treatment prior to commencement. | | | no clear expectation of treatment and a lack of knowledge. Mismatch of patient need and information delivery. | | sample limits generalisability. Lack of education description. Recommendation: patient centred flexible education provision. Verbal, visual and vicarious education delivery. |
| Inaguma et al 2006 Effects of an educational programme on the pre-dialysis period for patients with chronic renal failure. | i) Controlled Trial ii) 176 iii) Adult | Dialysis patients Education programme participants (n=70) Non-participants (n=106) | Renal function, biochemistry, planned initiation of treatment, hospitalisation duration and cost and modality selection. Self-perceived knowledge questionnaire. | | Two 2-hour lecture sessions. Multidisciplinary presentation by renal HCP and social worker including: renal function, renal failure, treatment options, blood results, diet welfare. Group presentation to 10 patients plus families. | Intervention group: Duration and cost of hospitalisation was significantly smaller. Significantly less temporary access. | | Limitation: Self-selection methodology. Knowledge questionnaire subjective. Recommendations: Increase understanding of education programme contents and regular intervention delivery. |
| Krespi et al 2004 Haemodialysis patient beliefs about renal failure | i) Questionnaire ii) 156 iii) Adult | Haemodialysis patients | Belief and belief prevalence regarding: renal failure, fluid and diet restrictions and haemodialysis. | | | Renal failure is attributed to lack of self-care and inadequate medical care. Lack of belief in the | | Limitations: Selective population not representative of wider renal population. Non-validated |

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| and its treatment | | | | | | necessity for fluid and diet control. Haemodialysis was viewed as externally imposed and dominating life. | | questionnaire utilisation. Recommendations: Patient-centred care, psycho-educational intervention to reduce negative beliefs and improve quality of life. |
| Korniewicz D, et al 1994 Evaluation of a haemodialysis patient education and support programme | i) RCT ii) 135 iii) Adult | Haemodialysis | Exercise of Self Care Agency Scale Sickness Impact Profile Haemodialysis Regimen Compliance Scale Inventory of Social Function Dean Alienation Scale | Orem's Theory of Self-Care | Twelve, 1 hour, hospitals based sessions, delivered one-to-one by a nurse including: self-care teaching and support, modification of self-image and coping skills. | At 6 months and 1 year: Increased physical and psychosocial adaptations on most scales ($P=0.05-0.01$) | | Limitation: Poor reporting. Drop out not described. Recommendation: Specific education delivery training for haemodialysis nurses. Development of patient and family support by peers. Community programmes directed at patient centred, patient focused education needs. |
| Kutner, N. & | i) RCT | Haemodialysis patients, <1year | Diet, fluid restriction & medication | Not reported | Two hospital based group sessions | At 2 months: | | Limitation: Short follow-up. Poor |

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| Brogan D. 1982 Evaluation of an experimental education programme for new dialysis patients | ii) 21 iii) Adult | on dialysis | concordance, self-rated on visual scales. Anxiety & Depression measured on the Zung Scale. Patient satisfaction, self-rated scale. | | lasting 4 hrs each, facilitated by the multidisciplinary team. | Increased concordance with diet regime ($P=0.2$) Increased concordance with fluid regime ($P=0.1$) Increased concordance with medication regime ($P=0.5$) Changes in: anxiety ($P=0.4$), depression ($P=0.5$), self-satisfaction ($P=0.1$), Locus of control ($P=0.3$). | | reporting. Small sample size. Only 52% of participants completed the study. |
| Leon, J. et al 2001 Can a nutritional intervention improve albumin levels among haemodialysis patients? A pilot study. | i) RCT ii) 83 iii) Adult | Haemodialysis | Diet concordance C-Reactive protein (CRP)(inflammatory status impact on albumin levels). | Not identified | Six, once monthly, hospital based, one-to-one, dietician delivered sessions. | At 6 months: Increased diet concordance. Improvements in mean albumin even with increased CRP ($P=0.01$); CRP effect on albumin ($P=0.83$). | | Limitation: Poor reporting. Small sample size. Recommendation: Improve and test in a larger sample and with multiple nutritional markers. |
| Lenz et al | I) Cross-Sectional | Pre-dialysis | Patients achieving National Kidney | | | Failure to achieve guidelines resulted | | Limitations: Single centre study, small |

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| 2005 Barriers to successful care for chronic kidney disease | Analysis ii) 198 iii) Adult | | Foundation guidelines for patients with chronic kidney disease (K/DOQI) based on biochemical results. | | | from: recent referral to a nephrologist (Odds Ratio (OR) 3.3, 95% CI 1.5 to 7.5; $P=0.004$), failure to attend clinic (OR 3.2, 95% CI 1.6 to 6.5; $P=0.001$), African American ethnicity (OR 2.2, 95% CI 1.1 to 4.6; $P=0.027$) diabetes (OR 2.2, 95% CI 1.1 to 4.5; $P=0.030$) and advanced renal failure (OR 2.2, 95% CI 1.1 to 4.4; $P=0.032$). | | sample size limits power associated with poorer outcomes. Retrospective analysis shows association not causation. Recommendations: Raised awareness of chronic kidney disease in primary care, early nephrology referral, patient and physician education and exploration of cultural and socio-economic barriers. |
| Manns , B et al 2005 The impact of education on chronic kidney disease patients' plans to initiate dialysis with self- | i) RCT ii) 70: 35 Intervention and 35 Control Group iii) Adult | CKD Stage 4-5, pre-dialysis | Questionnaire to assess patients Intention to Treat with self-care dialysis. Questionnaire to assess patients' knowledge & attitude, and attitude toward self-care dialysis. | Problem Based Learning | Hospital based small group format: Week 1, educational booklet & video; Week 2, Interactive Discussion of 90 minutes involving the nephrologist and pre-dialysis nurse. | At 4 weeks: Increase in patients wanting to start self-care dialysis (adjusted OR, 10.2; 95%CI, 2.0-50.3) Increased knowledge (explanation [$P<0.001$] & understanding self-care [$P=0.02$] Self-efficacy (training | Increase in self-care selection | Limitation: Short follow up. Questionnaire validity not reported Recommendation: Use of a two phase educational intervention |

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| care dialysis: A randomized control trial | | | | | | [P=0.02] & performing self-care [P=0.02]) | | |
| Mathers T. 1999 Effects of psychosocial education on adaptation in elderly haemodialysis patients | i) RCT ii) 10 iii) Adult, 65yrs or over | Haemodialysis patients | Psychological Adjustment to Illness Scale- Self-Report (PAIS-SR) | Behavioural-Orientated Approach | Five, twenty minute, audiotape with companion text sessions, with a researcher available to answer questions. Sessions aimed at cognitive reappraisal & goal setting | 30 days post intervention: Increased adaptation to kidney disease (P=NS) | | Limitation: Short follow-up. Poor reporting. Forty per cent drop out, without description. Recommendation: Repeat study upon larger and longitudinal basis. Reinforce sessions with take home literature and conduct a needs assessment study of stressors in elderly dialysis patients. |
| McLaughlin et al 2003 Why patients with ESRD do not select self-care dialysis | i) Cross Sectional Survey ii) 173 | Haemodialysis patients Questionnaire developed with face and content validity | Reason patients choose not to perform self-care dialysis. | | | Most prevalent barriers included: Knowledge: lack of satisfactory treatment explanation. | | Limitations: no comparison to self-care patient perceptions resulting in selection bias. |

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| as a treatment options. | iii) Adult | checked. | | | | Attitude: patients shouldn't dialysis without direct medical supervision (adjusted OR 1.14, 1.05 to 1.24; $P=0.01$) and fear of social isolation (adjusted OR 3.36, 1.32 to 8.49; $P<0.05$). | | Recommendations: Evaluation of educational interventions aimed at improving knowledge, skills and attitudes to self-care. |
| McLaughlin et al 2008 Why do patients choose self-care dialysis? | i) Randomised Control Trial ii) 70 iii) Adult | Pre-dialysis Standard pre-dialysis education (n=35) Multifaceted education intervention (n=35) | Questionnaire pre and post intervention to determine perceived self-care advantages and modality preference. | | Positive framing of self-care, educational intervention. Four written manuals, 15 minute self-care video, positive self-care vicarious experience, interactive HCP lead group teaching session including family (problem solving, justification of dialysis choice) selective video presentation. | Patients who learned that self-care enhanced freedom (OR 9.1, 2.0 to 41.3; $P=0.004$) lifestyle (OR 7.0, 1.6 to 29.7; $P=0.008$) and control (OR 4.3, 0.9 to 19.1; $P=0.058$) and attended the group session were more likely to choose self-care dialysis. A combination of predisposing and enabling component positively changed perceptions of self-care advantages. | | Limitations: Intended not actual treatment end point. Planned start pre-dialysis population so not applicable to acute start. |
| Mehrotra et al 2005 Patient education and access of | i) Prospective Cohort Survey ii) 428 | Dialysis patients Effect of pre-dialysis processes on treatment | Modality selection survey. | | | Patients not aware of kidney disease (36%) Not seeing a nephrologist <4 months pre-dialysis | | Limitations: Low response rate (31%), small sample size limiting poorer outcome findings, |

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| ESRD patients to renal replacement therapies beyond in-centre haemodialysis | iii) Adult | choice. | | | | <p>commencement (16%)</p> <p>Treatment option presentation <1-month pre-dialysis commencement (48%)</p> <p>Treatment options not presented:</p> <p>PD (66%) Home Haemodialysis (88%) and Transplantation (74%)</p> <p>Selection of PD was associated with PD information presentation (OR 0.07, 95% CI 0.02 to 0.21; $P=0.0001$) and time spent discussing treatment options (OR 0.06, 95% CI 0.01 to 0.28; $P=0.002$).</p> | | <p>limited population diversity, cross sectional nature identifies association's not causal factors, potential over estimation of lack of education provision.</p> <p>Recommendations:</p> <p>Need to provide patient education to optimise self-care treatment.</p> |
| Mendelssohn et al 2001 What do American Nephrologist think about dialysis modality selection? | i) Prospective Cohort Survey ii) 240 iii) Adult | Nephrologist | Nephrologist demographics, factors influencing modality recommendations, opinion of modality distribution and optimum treatment distribution. | | | <p>Most important factors influencing:</p> <p>Modality recommendations: personal opinion, quality of life, morbidity and mortality.</p> | | <p>Limitations: Low response rate (47%), opinion may not represent actual practice, lack of sensitivity and validity of survey instrument and only a cross section of beliefs</p> |

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| | | | | | | <p>HD considered over used and PD and transplant under used.</p> <p>Hypothetical optimal PD use was three times the actual use.</p> | | <p>gained in a period of rapid change.</p> <p>Recommendation: utilisation of the framework to assess patient and provider interactions influencing modality selection.</p> |
| <p>Nulson RS, Yaqoob MM, Mahon A, Stoby-Fields M, Kelly M, Varagunam M,</p> <p>2008</p> <p>Prevalence of cognitive impairment in patients attending pre-dialysis clinic</p> | <p>i) Cross sectional audit</p> <p>ii) 132</p> <p>iii) Adult</p> | <p>Pre-dialysis</p> <p>CKD Stage 4 & 5</p> | <p>Mini mental state examination</p> <p>Biochemistry blood test</p> | | | <p>Positive association between baseline eGFR and cognitive impairment (p=0.032)</p> <p>Cognitively impaired group were older (p=0.005) and most significant predictor of low cognitive score.</p> <p>Greater cognitive impairment showed trends towards higher mortality, less self-care dialysis, less pre-dialysis time.</p> <p>Cognitive impairment impact on individuals' ability to participate in</p> | | <p>Limitations:</p> <p>Single centre study.</p> <p>Older patient age group range not identified.</p> <p>Recommendation:</p> <p>Cognitive function assessment, especially in older patients making treatment decisions.</p> |

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| | | | | | | <p>treatment and make informed decisions.</p> <p>The prevalence and impact of poor cognition are under recognised.</p> | | |
| <p>Ormandy, P</p> <p>2008</p> <p>Information topics important to chronic kidney disease patients: A systematic review</p> | <p>i) Systematic Review: Qualitative & quantitative methods</p> <p>ii) 25 studies (22 research, 1 literature review and 2 personal accounts). Range within studies 6-197</p> <p>iv) Not identified</p> | Chronic kidney disease | Patient identified information needs. | | | <p>Thirteen information topics important to participants were identified:</p> <ol style="list-style-type: none"> 1) Chronic kidney disease information 2) Renal replacement therapy 3) Physical symptoms & body image 4) Complications of both disease and treatment 5) Family & social life 6) Work & finance 7) Diet & fluid restrictions | | <p>Fails to identify which information topics are required at any given point in the patients' renal journey.</p> <p>No demographic variations in information topics identified.</p> <p>Recommendation to include participants' clinical information to understand their information needs as their disease progresses.</p> |

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| | | | | | | 8) Medication 9) Tests and blood results 10) Psychological impact 11) Other patients experience 12) Patient organisations 13) Service provision | | |
| Paterson B 2001 The myth of empowerment in chronic illness. | i) Grounded Theory analysis of patient audio-recorded decision-making over three weeks ii) iii) Adult | Type I Diabetes (15 years or over) | Self-care decision-making. | | | Practitioners subtly and covertly contradict empowerment goals in interaction with diabetics. Practitioners discount experiential knowledge despite intentions to foster participatory decision-making. Resources for informed decision-making are not provided. | | Limitations: lack of ethnic diversity, lack of recommendations. |
| Perry E, et al | i) RCT ii) 203 | Haemodialysis | Completion of advanced directives (AD), comfort with discussing AD, | Oral cultural traditions | Group 1: individual face-to-face peer mentoring, and supportive phone | At 2-4 months: Increased completion of ADs for Group 1 compared with Group 2 | | Limitation: Limited follow-up, non-validated measures, social |

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| 2005 Peer mentoring: A culturally sensitive approach to end-of-life planning for long-term dialysis patients | iii) Adult | | psychological assessment of: depression, well-being, acceptance of death, suicidal ideation and anxiety. | | calls. Group 2: Printed information | and the control group ($P=0.01$) Increased level of discussion comfort for Group 1 compared with Group 2 and Control group ($P=0.05$) Increased Group 1 effects for African Americans: completing ADs ($P<0.001$), discussion comfort ($P<0.01$), increased wellbeing ($P=0.05$), decreased anxiety ($P=0.05$), increased death acceptance ($P=0.2$). | | workers affected randomisation, no control of contact time. Recommendation: Use of oral traditions and personal contact for the transmission of information and storytelling address cultural values, alley anxiety and acceptance. |
| Ramsdell R & Annis C 1996 Patient education: A continuing repetitive process | i) Cohort Study: Pre & Post Intervention Survey ii) | Haemodialysis | Retention of important information | | HCP presented 4 topics based on patient views of education need, each topic was presented for 1 week at each of the 3 dialysis sessions. These included: diet, | Significantly increased knowledge of all topics was identified (knowledge 57.7% to 85.6%; Access care 92.1% to 97.7%; medication therapy 6.77% to 86.8%; fluid restriction 83.79% to | | Limitations: short follow-up, small sample size, lack of objective measures and verbalisation may not reflect actual behaviour. Recommendations: |

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| | iii) Adult | | | | fluid restriction, medication and access care. | 92.29%). Documentation of patient education improved. The repetitive process reduced inter-dialytic weight gain and better phosphorous control. Increased compliance. Self-care behaviours. | | Simple repetitive education engages patients, develops relationships and improves retention of important information. |
| Sharp et al 2005 A cognitive behavioural group approach to enhance adherence to haemodialysis fluid restrictions: A randomised control trial | i) RCT ii) 56 iii) Adult | Haemodialysis patients | Fluid restriction concordance, measured by interdialytic weight gains. SF-36 & HADS health status, belief and emotional functioning questionnaires. Health attribution associated with fluid restrictions measured. | Cognitive behavioural therapy | Four 60-minute sessions with a supervised trainee psychologist including: Information, self-regulation, self-monitoring skills, goal setting, stress management and relaxation techniques, thought records and a support manual. | At 4 weeks follow-up: Increased fluid concordance NS (mean change of -0.25Kg; 95% CI, -0.66-0.16) Specific significant changes to SF36 health status: Mental Health, (mean change 12.64; 95% CI, 5.59 to 19.69) Role Emotional (mean change 18.78; 95% CI, 8.62 to 28.95) Attribution (mean change, -12.33; 95% CI, -12.07 to -3.59) | N/A | Limitation: Short follow-up Recommendation: Group based CBT is effective in enhancing adherence to haemodialysis fluid restrictions. |
| Starzomski R | i) Case Study of an education | Pre-dialysis adults (n=18) | Process, structure and content of | | Initial 1-hour multidisciplinary interview attended | Kidney failure information needed | | Limitations: Small sample size, lack of theoretical |

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| 1986 Patient and staff involvement in decisions for ESRD treatment | programme ii) 25 iii) Adult | Post- dialysis commencement (n=7) | programme. | | with family and education manual supplied. Kidney function session ½ -1 hour. Treatment options 2-3 hours Dietician 1-2 hours Unit tour ½ -1 hour Home visit 1-2 hours Minimal care unit visit 1 hour Peer meeting 1 hour | earlier. Video and manual explained treatment options well. Diet list of food to avoid, portion size interpreting labels useful but no menus for diabetics. Family involvement helpful and peer input desired. Education helpful in decision-making. | | foundation to education. Recommendations: Education 1 year pre-dialysis, PD peer meeting, Improving team work, family counselling at treatment commencement. |
| Tanner , J et al 1998 The effect of a self-monitoring tool on self-efficacy, health beliefs, and adherence in patients receiving | i) RCT ii) 40 iii) Adult | Patients on Haemodialysis for 2 months, with 1 month+ non-concordance with fluid and diet restrictions | Pre-test / post-test measures including: Self-efficacy / Health Belief Survey. The knowledge survey. | Self-efficacy | Six, once monthly, hospital based, individual, dietician delivered, sessions including: feedback, rewards & contracts, goal setting. | At 6 months: Increased knowledge ($P=0.008$); Improvement in diet concordance ($P=NS$), fluid concordance ($P=NS$), health beliefs & self-efficacy ($P=NS$). | | Limitation: Small sample size. Short follow-up. Recommendation: Research using additional measures to explore the effect of increased frequency and duration of intervention. |

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| haemodialysis | | | | | | | | |
| Tawney K et al 2000 The Life Readiness Program: A physical rehabilitation program for patients on haemodialysis | i) RCT ii) 82 iii) Adult | Haemodialysis | Kidney Disease Quality of Life (Short form) | Rehabilitation Model | A dietician provided nine 15-30 minute one-to-one sessions in the hospital setting, including: structured counselling on physical activity with goal setting, problem solving and written information. | At 6 months: Increased physical function reported ($P=0.04$) | | Limitation: Physical function not clinically assessed. |
| Tsay S. 2003 Self-efficacy training for patients with end-stage renal disease | i) RCT ii) 62 iii) Adult, aged 20-65 years | Haemodialysis patients | Interdialytic weight gain for fluid intake concordance | Social Learning Theory | Hospital based 12 one hour individual sessions including: self-efficacy training, education, performance, mastery, experience sharing and stress management, diet and fluid diary for review | Increased fluid concordance at 1, 3 & 6 months follow-up ($P=0.006$) | | Limitation: Limited follow-up Recommendation: Self-efficacy training is effective for haemodialysis patients' fluid control. |
| Tsay S & Hung L | i) RCT ii) 50 | Haemodialysis patients | Empowerment Scale Self-care efficacy measure | Patient Empowerment | 12 one-to-one sessions with a clinical nurse specialist including: Information pack; | At 6 weeks follow-up: Increased empowerment | N/A | Limitation: Short follow-up period |

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| 2004 Empowerment of patients with end-stage renal disease: a randomised control trial | iii) Adult | | Beck Depression Inventory | | consultation sessions covering self-management skills, problem solving, coping, social support, self-awareness, goal setting and stress management. | ($P=0.001$) Increased self-efficacy ($P=0.002$) Increased reported less depression ($P=0.03$) | | Recommendation: Patient empowerment programme provides a non-invasive intervention and is an effective intervention model. |
| Tsay s. et al 2005 Effects of an adaptation training programme for patients with end-stage renal disease | i) RCT ii) 57 iii) Adult | Haemodialysis for 6 month + | Haemodialysis Stressor Scale and Beck Depression Inventory and SF36 Quality of Life scale. | Cognitive behavioural therapy and transactional theory | Eight hospitals based group sessions lasting 2 hours, components included: cognitive behavioural modification, problem solving, stress management & weekly diary. | At 3 months: decreased perceived stress ($P=0.005$), depression ($P=0.001$) and increased quality of life ($P=0.02$) | | Limitations: 17% failure to complete the whole course. Limited follow-up. Recommendation: Nurses could be trained to deliver group sessions in haemodialysis units and improve quality of care significantly |
| Tucker c. 1989 The effect of | i) RCT ii) 103 iii) Adults | Haemodialysis | Interdialytic weight gain Social Support Scale | Social Learning Theory | Hospital based one-to-one with nurse educator over six weeks. Three groups Group 1 Control included: self-monitoring, praise and monetary | At 18 weeks: Increased fluid concordance Group 3 compared with Group 1 Control ($P=0.05$) and Group 2 (0.01), and for Group 3 compared to Group 1 Control | | Limitation: Poor reporting. Inconsistent implementation methods. Dropout not described. |

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| behavioural intervention with Patients, Nurses, and Family Members on dietary noncompliance in chronic hemodialysis patients | | | | | reward. Group 2 included: as above plus visual behaviour control techniques. Group 3 included: as above plus family support. | ($P=0.05$). Increased family support perceived in Group 3 compared with the other groups ($P<0.001$) | | Recommendation: Monitoring and reinforcing contingency for nurses to increase follow-through concordance in future studies. |
| van Vilsteren et al 2005 The effects of a low-to-moderate intensity pre-conditioning exercise programme linked with exercise counselling for sedentary haemodialysis patients in The Netherlands results of a randomized clinical trial | i) RCT ii) 96 iii) Adult | Haemodialysis | SF36 (short form) quality of life questionnaire Physical fitness: reaction times, dexterity, exercise capacity, muscle strength. | Transtheoretical motivational interviewing & health counselling model. | An exercise counsellor provided 4 individual, hospital based sessions including an: Exercise programme, motivational counselling, coping mechanisms. | At three months: Increased reaction time ($P=0.002$), increased muscle strength ($P=0.05$), increased dexterity ($P=0.48$), increased exercise capacity ($P=0.14$), increased self-efficacy ($P=0.002$), increased quality of life for pain ($P=0.001$), increased vitality ($P=0.001$), increased health perception ($P=0.001$) and increased physiological condition for Kt/V ($P=0.05$) | | Limitation: Follow-up is limited Recommendation: Stimulation of more physical activity should receive more emphasis in haemodialysis units. |

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| Winterbottom et al 2007 Evaluating the quality of patient leaflets about renal replacement therapy across UK renal units. | i) Cross Sectional Survey ii) Questionnaire (n=67) Leaflets used supplied from units (n=32) iii) Renal Units | English Renal Units | Audit the provision of information and assess the quality of written information about treatment options. | | | Most leaflets were: difficult to understand; rarely included risk information or treatment limitations; no leaflets included decision-making. Leaflets primary goal was to inform. | | Limitations: inability to assess effectiveness of resources to facilitate patient needs Recommendations: research needs to identify effective resources and when they are beneficial to patients. Centralised resource for information development for education, decision-making and self-management. |
| Wuerth et al 2002 Patients, descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or haemodialysis | i) Structured Interview ii) 40 iii) Adult | Dialysis Patients PD (n=20) HD (n=20) | Taxonomy of patient influences and concerns. | | Structured education programme. | <i>Impact of pre-dialysis education (n=22):</i> PD (n=16), HD (n=6). Attendees selecting self-care treatment (82%). <i>Other influences:</i> doctor (n=33), written information (n=16), significant other (n=12) <i>Autonomy/Control:</i> In | | Limitations: Retrospective nature relies on patient recall and may be impacted by uraemia, no description of educational intervention, small sample size. Recommendations: All renal patients |

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| | | | | | | <p>PD: privacy of own home (n=19), flexibility (n=19). In HD: planned schedule (n=7), professional care (n=5)</p> <p>Treatment Factors: In PD: Infection concern (n=6), Don't like blood (n=5), done at night whilst sleeping (n=5). In HD: duration of treatment (n=6), centre based treatment (n=5), don't want abdominal tube (n=5). Treatment choice given: PD (n=20), HD (n=8)</p> | | <p>are provided with appropriate education material, inclusion of family in education provision, education of acute start patients, objective written material to overcome bias, staff encouragement to support education interventions.</p> |
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Renal Patient Journey

The reviews highlight issues individuals with renal failure face during their renal education and treatment decision-making journey. This was found to involve frustration, inconvenience, loss of control, self-blame and depression (Krespi et al 2004). Krespi et al, surmise that this results from imposed external forces and results in a failure to adjust. Potentially compounding these challenging psychological states is an apparent mismatch in education delivery and patient need. The result is identified as a lack of knowledge and no clear expectation of treatment (Iles-Smith 2005). However, information seeking within this cohort was found to relate to positive adaptation to chronic illness. It could be argued that the underlying foundation for information seeking may be indicative of existing self-efficacy behaviour. Nonetheless, education delivery was ad-hoc and information seeking may be more indicative of a failure to fulfil renal patients' education need adequately.

Where education interventions have been supplied, renal knowledge levels have been found to improve significantly (Gomez 1999). Following a standard protocol educational intervention, the greatest levels of knowledge were found in those individuals less than 65 years of age and those with a better creatinine clearance rate (Gomez et al 1999). In a prospective cohort study, renal patients receiving a pre-dialysis education programme had improved knowledge of their illness and its treatment, resulting in a greater ability to participate in modality selection (Starzomski 1996). This has implications for the need to adapt education components or delivery method dependent on disease progression, and with the older age group. With an

increasingly elderly renal population demographic (Renal Registry 2008), it is imperative that appropriate tailoring of interventions is incorporated into education development.

Bat-Avi (1989) eloquently highlights the fears, shock and isolation of a renal failure diagnosis. The need for, and importance of pre-dialysis education, combined with family involvement and support systems is advocated. This suggests consideration should be given to carer education and its incorporation into group education delivery, in addition to existing accompaniment of patients in out-patient clinics.

These studies highlight the importance of acknowledging individuals' life and care contexts and the impact they will have on individual self-care desirability. The need to adapt education intervention delivery to accommodate individuals and carers needs has implications for the development and delivery of pre-dialysis educational interventions.

Renal Educational Interventions

18 trials identified by Mason et al define a theoretical basis; however 14 different theoretical foundations are identified. Interventions are guided by theory. Unfortunately poor description, overlapping theories and concepts, and multiple implementation methods lead to difficulty in determining the resultant effect of specific theories. Reviewing these articles individually feeds into the findings discussed within the progressive stages of CKD education. The range of articles is supplemented by the wider renal literature allowing inferences and recommendations to be drawn.

The use of a single education session in pre-dialysis patients was found to offer support and encourage collaboration, and was effective in increasing knowledge, delaying time to dialysis, and increasing survival rates in long-term follow up. Interventions were found to be more successful when incorporated into routine care. Face-to-face interventions, both individual and group format, and peer mentoring were found to result in positive outcomes. Patients' fluctuating levels of wellness during their renal journey, and the non-reversible nature of renal disease, result in different educational needs dependant on their stage of renal failure. With a focus on the implications of findings for the pre-dialysis population, the wider literature is explored. The studies relate to; Early Chronic Kidney Disease (CKD Stages 1-3); Pre-dialysis (CKD Stage 3-4); and End Stage Renal Failure (CKD Stage 5) where dialysis is imminent or instituted.

Early Chronic Kidney Disease (Stage1-3)

The RCTs within Mason's review fail to examine educational interventions for early stage kidney disease patients. In the wider renal literature, early detection of kidney disease and education provision has been explored.

Four studies have identified the benefits of early referral to nephrology services. They describe the utilisation of multidisciplinary resources within a structured education format as central to improved patient outcome, at commencement of dialysis (Goldstein et al 2004, Inaguma et al 2006, Starzomski 1986). Barriers to achieving this early intervention

recommendation have been investigated (Lenz et al 2005). Lenz et al identify a number of contributory factors in patients' failure to achieve national guidelines for renal biochemistry results. These included late referral to nephrology, advanced renal failure, failure to attend clinic appointments and African American ethnicity. The cultural diversity and delivery method for renal education need to address a diverse population and adapt to local need. Recommendations to overcome these potential barriers include: early referral to nephrologists', increased patient and professional education; raising levels of awareness among primary care providers, and research into cultural and socioeconomic barriers.

Some of these issues are being addressed through government and patient charity activity. Detection of chronic kidney disease in primary care has now been incorporated into the Quality and Outcomes Framework (DoH 2006c) in the form of a formula-based estimation of glomerular filtration rate (eGFR), which aims to identify people at risk or in the early stages of kidney disease. Thus the opportunity to minimise kidney damage and reduce cardiovascular risk can be maximised through treatment and lifestyle changes. The resulting effect, it is hoped, will be a reduction in the impact of CKD for both patients and the NHS. However, empirical evidence would suggest an initial dramatic increase in referrals due to eGFR reporting.

One of the leading kidney patient charities, Kidney Research UK, has produced the ABLE project (A Better Life through Education and Empowerment). This programme was designed to educate individuals at increased risk of renal disease and prevent kidney disease. It is focused on

the African Caribbean and Asian communities and is supported by the Department of Health. Project follow-up found that a single education intervention provided by lay individuals within community settings did not impact on prevention behaviour. However, the introduction of Quality Outcome Framework's (DoH 2006c) rewarding GPs for the detection of renal failure markers was indicated as the most likely influence on the marginal improvement in detection seen.

Pre-Dialysis (Stage 4-5)

The impact of a single pre-dialysis education session was explored in one RCT and included: a slide show, booklet and psychosocial support, found it had a significantly positive impact on 'time to dialysis' ($p=0.05$) and participants knowledge levels ($p<0.001$) (Binik et al, 1993). Further exploration of the study data for long-term knowledge retention was conducted by the same research team (Devins et al, 2000). They found increased knowledge levels for early and late referral intervention groups, suggesting the educational intervention was indeed effective. However, the late referral control group also had similar increased knowledge levels. This may reflect a differing approach to education delivery in early and late presenters. The increased knowledge levels persisted at 18 months ($p=0.006$), 30 months ($p<0.001$), 42 months ($p<0.001$) and 54 months ($p<0.001$). However, the study fails to identify any theoretical foundation for education development or delivery.

The 18-month data were additionally investigated for anxiety & depression scores and self-rated social support (Devins 2003). The follow-up study found no significant difference in these additional measures. The findings do however suggest that HCP follow-up support is important for those individuals who cope by avoiding information perceived to be threatening.

The long-term, 20-year follow-up of the original study (Devins 2005) found increased knowledge, dialysis start delayed by 8 months (chi-square-change [1] = 4.39; $P = 0.036$; hazard ratio, 1.35; 95% CI, 1.02 to 1.775) and survival rates extended by 2.25 years (chi-square-change [1] = 3.75; $P = 0.053$; hazard ratio, 1.32; 95% CI, 1.0 to 1.74). Interestingly, early referral, identified in current guidelines, was found to infer no survival advantage. However, the impact on treatment decision-making may be influential.

The extensive analysis and extended follow-up of these studies (Binik 1993, Devins 2000, 2003 & 2005) gives meaningful insight into the impact of a psycho-educational intervention on a particular cohort but is limited by the single centre study and repeated use of data.

Problem based Learning Theory, provides the foundation for an RCT exploring the impact of education on participants plans to commence self-care dialysis (Manns et al 2005). Two small group sessions provided 1) a video and booklet on self-care treatment and 2) an interactive discussion involving the nephrologist and pre-dialysis nurse. The study identifies a significant increase in participants wanting to start self-care dialysis (adjusted OR, 10.2; 95%CI, 2.0-50.3), increased knowledge (explanation [$P < 0.001$] & understanding self-care [$P = 0.02$] and Self-efficacy (training [$P = 0.02$] &

performing self-care [$P=0.02$]). However, the short follow-up fails to identify if the intention to self-care comes to fruition. The impact of declining health and cognitive capacity combined with increasing symptom burden, as the renal journey progresses, may result in a re-evaluation of self-care capacity and desire.

The need for early and on-going education of patients has been identified in the self-care education literature as central to enhancing self-efficacy and self-management. Patient information leaflets are widely utilised in the UK to provide renal specific information. The resources produced have been defined as incomplete and incomprehensible and deemed to be difficult to understand (Winterbottom et al 2007). There is a lack of risk information and treatment limitations and a failure to include any techniques to assist patient decision-making. With complex treatment decisions to make, the authors argue that the provision of a decision-making tool could clarify and simplify the situation.

Winterbottom et al (2007) advocates the minimisation of bias in information processing, risk/benefit analysis for each treatment option and identification of the decisions to be made by the patient. Winterbottom et al argue that information aids can increase knowledge, reduce anxiety and improve satisfaction when they are evidence-based, accurate and comprehensible. Education, treatment choice and self-management are central goals of educational interventions and Winterbottom et al, advocate the use of established guidelines, on the development of effective written information.

This has important implications for the sourcing or development of information utilised in pre-dialysis education interventions.

Starzomski (1986), focuses on the evaluation of the structure, process and content of complex educational interventions. The components of the intervention include an initial interview with a clinical nurse specialist, an education manual including videos, a renal patient magazine, expert patient contact and facility tours. Evaluation of the intervention by the planned pre-dialysis patients was far more favourable than those of the unplanned patients, who had already started acute dialysis treatment. This highlights the need to adapt education according to the patient's disease progression. The differing learning needs of individuals must be recognised. However, HCPs must also recognise the varying needs across an individual's renal journey in relation to disease progression, fluctuating wellness and circumstantial changes.

The effect of multidisciplinary pre-dialysis care on patient morbidity and mortality was identified by Goldstein et al (2004). The only significant independent determinants of health status were found to be age, cardiovascular history and importantly multidisciplinary clinic attendance as the only variable that can be manipulated. Improved acceptance of dialysis need, resulted in earlier decision-making and vascular access planning. As with many complex interventions, pinpointing specific components associated with improved outcome is troublesome. Goldstein et al (2004) suggests that the resultant effects stem from the sum of the parts. The sum effect of the

components being improved albumin levels (3.7g/dL [37g/L] versus 3.3 g/dL, $P < 0.01$) at initiation of dialysis, reduction in hospitalisation (7.0 versus 69.7 d/patient/year; $P < 0.01$) and reduced mortality rates (2% versus 23%; $P < 0.01$). These findings show there are both short and longer-term benefits of multidisciplinary clinics, and as such, emphasises the need for careful consideration of their role as it relates to pre-dialysis education effectiveness.

Patients' beliefs about renal failure highlight the need for patients to understand the cause of their renal failure, if they are to adjust and regain an internal locus of control (Krespi et al 2004). Participants presented an overall picture of a condition and context over which they had no control. This need for ownership of restrictions and meaning to renal events, it is suggested could be achieved through psycho-educational interventions, resulting in a reduction of negative beliefs and improvement in quality of life. Unfortunately no reference is made to any educational input patients may or may not have received.

Family input in the decision-making process was found amongst individuals opting for self-care dialysis (Wuerth et al 2002). Family support was a significant factor in self-care selection, and as such underscores the necessity to involve family, partners and carers at the education stage. The With a home-based treatment option family dynamics were found to impact on technique failure rates, highlighting the importance of family involvement. The longer term benefits of family involvement in education are advocated (Wuerth et al 2002).

The need for support was identified by Starzomski (1996), who introduced an educational intervention including: kidney function session, treatment options, dietitian, dialysis unit tour, home visit, minimal care visit and a peer meeting. The benefits of informal social support from both patients and professionals, created within an education programme group were recognised. Peer support and the increased potential for vicarious learning afforded by group-based educational interventions fits within the key framework elements of self-efficacy theory (Bandura 1977). A patient-centred, flexible approach to education delivery, involving the use of expert patients to provide vicarious learning is recommended (Mendelssohn et al 2001), and this ties in with the benefits of support highlighted and self-management study findings (Barlow et al 2005, Lorig 2001). Mason et al (2008) concluded that consideration of a single session, patient-centred educational intervention, which is structured to encourage collaboration, is worthy of merit.

End stage (Stage 5)

In pre-dialysis education the emphasis has been shown to be on increasing kidney disease and treatment knowledge, and facilitating informed treatment decision-making. The focus shifts in post-dialysis commencement studies, with diet and fluid concordance becoming most prominent. However, there are valuable insights to be gained from this literature.

Studies range from a single dietetic session, including behavioural control, which increased diet concordance at 3 months but failed to impact on

calcium phosphate product (Ashurst & Dobbie, 2003). To, a more extensive behaviour modification and health beliefs based intervention, delivered weekly over a 6 week period (Cummings 1981). The intervention resulted in increased diet ($p=0.05$) and fluid concordance ($p=0.05$) at the end of the study but by 3 months follow-up there was no significant difference. The authors conclude that health beliefs were not predictive of concordance. These findings may indicate a degree of transience, associated with longer-term intervention impact, and highlight the need for on-going information delivery.

Improved diet and fluid concordance has been identified in a range of short term, ≤ 6 month follow-up, studies. These studies indicate a theoretical foundation to education delivery including: Social Learning Theory (Diemling 1984, Tsay 2003 & Tucker 1989), Cognitive Behavioural Therapy (Sharp et al 2005) and Self-efficacy Theory (Tanner et al 1998). Other studies indicate no theoretical foundation (Kutner & Brogan 1982) Leon (2001), Ford (2004) and Sharp et al (2005).

These studies illustrate that the diet and fluid concordance interventions that were most successful were found to include, intensive and complex interventions utilising social theory. This is an important consideration for the future development and delivery of educational interventions. Additionally, education delivery was found to be more successful when provided during clinic or dialysis visits, negating the need for extra visits. This imperative requires careful thought about how it will apply to a pre-treatment cohort. There is a balance to be achieved between successful interventions such as

Korniewicz & O'Brien's (1994), that involved 1 hour's educational input over 12 consecutive sessions, and the impact on the service user, HCP and financial resources. It may be that such a format is only practicable with individuals already receiving routine outpatient dialysis.

Tsay et al (2004 & 2005) conducted two studies to explore patient empowerment and cognitive behavioural therapy respectively. The empowerment study (2004) though producing significant results; increased empowerment ($p=0.001$), self-efficacy ($p=0.002$) and reduced depression reporting ($p=0.03$), consisted of 12 sessions and is limited by a short follow up. The impact of patient empowerment on self-efficacy levels is an important constituent to consider in education delivery and individuals ability to cope with their longer-term renal journey. Supporting these longer-term considerations is Tsay et al's second study.

The patient adaptation study (2005), run in 8 once weekly small group sessions, focused on coping with stressors. Participant reported a decrease in perceived stress ($p=0.005$), depression ($p=0.001$) and increased quality of life ($p=0.02$).

Coping and health perception are issues illustrated by two exercise studies (Tawney et al 2000, van Vilsteren et al 2005). Exercise counsellors delivered an exercise-training programme to haemodialysis patients based on a Transtheoretical motivational interviewing theory foundation, over four sessions, including an exercise programme and counselling. Aside from the physical improvement, summarised in Table 2.0.4, the increase in self-efficacy ($p=0.002$) and general health perception ($p=0.021$) are important

outcomes relevant to a pre-dialysis educational intervention. These findings are supported by Tawney et al (2000) who identifies increased physical function ($p=0.04$) following a rehabilitation model intervention, including counselling, goal setting and an exercise programme. It may be that these elements can help to build individuals' confidence to cope with their changing healthcare needs. Goal setting is a fundamental component of Mathers (1999), behaviour oriented approach to education delivery. Increased adaptation levels were identified, however because the sample size is particularly small, six individuals, no significance was identified.

Patient education as a continuing and repetitive process has been explored (Ramsdell & Annis 1996). This study highlights the effects of uraemia on the patients' cognitive ability to comprehend information; it was found to reduce attention span and impacted negatively on memory. Advanced age has been identified as compounding these difficulties. Indeed, Nulsen et al (2008) found age to be the most significant predictor of low cognitive score ($p=0.005$). Hence the educational intervention presented by nursing staff was based on the use of repetition. This is an important consideration in pre-dialysis cohort education. Fluctuating and declining renal function require ongoing and if necessary repetitious presentation of information. This approach, as a component of a continued complex educational intervention aimed at increasing patient self-efficacy, could help maintain and extend the knowledge base of patients. It may also assist patients to attain their desired level of self-efficacy. However, as professionals enhancing self-efficacy, HCPs must be aware of the rights of those individuals who, for whatever

reason, decide that the proposed behaviour (e.g. concordance) does not have a personally desirable outcome, and respect those decisions.

Self-care studies explore the benefits of patients working in partnership with their health care team. Self-management interventions, in essence, allow patients to develop resilience and resourcefulness but this can only operate successfully when patients and HCP work together. Hence a fine balance must prevail if the patient-professional partnership is to promote self-efficacy and self-management, through education and informed choice.

Only one study explored the use of trained peers (Perry et al 2005) to compare Advanced Directive (AD) completion. It is interesting to note that not only were more ADs completed following peer rather than social worker intervention ($p=0.01$), crucially there was an increase in African Americans completing AD ($p<0.001$). This would indicate that the ability to relate to those delivering the information has an impact and that cultural sensitivity and homogeneity is important.

Renal Treatment Decision-Making

Treatment decision-making is an inevitable element of individuals' pre-dialysis journey being explored in this thesis. The lack of decision-making theory identified in the self-care literature is mirrored in the renal literature. This section of the chapter therefore focuses initially on nephrologists' treatment decision-making beliefs, before then exploring impacts on patient decision-making. The current decline (UK Renal Registry 2008) in self-care

treatment selection is considered, and potential influences acting upon it examined. Finally, the effect of educational input, in terms of timing, delivery, quality, and impact on informed decision-making, is discussed.

Health Care Professionals' Beliefs

Curtin & Mapes (2005) explored the self-care and self-management domains of patients' lives and suggest that in relation to their chronic renal disease, individuals perceive nephrologists as a central and key character in their illness journey. However, doctors expressed the view that they were information givers, and as such, outside the patients' sphere of influence. This dichotomy in perception leads to a potential underestimation of the effect of the patient-doctor relationship on treatment choices (Curtin & Mapes 2005). This is an important consideration to address in developing MDT delivered education.

A consensus of belief has been shown amongst nephrologists that about one third of patients should be treated with peritoneal dialysis (Mendelssohn 2001). Paradoxically, it may be physician predisposition that denies patients information relating to peritoneal dialysis as a choice. A number of authors have commented on the unsubstantiated belief of some nephrologists, that peritoneal dialysis is an inferior form of treatment and that certain patient groups are seen unfairly as inappropriate candidates for peritoneal dialysis (Mendelssohn et al 2001, Wuerth et al 2002). The decreasing utilisation of self-care peritoneal dialysis, nephrologists cite as being associated with an

increase in obesity, diabetes and living alone (Mehrotra et al 2005). However, there is conflict in the research findings, as others suggest these need not be barriers to successful PD utilisation (Harris et al 2005).

Research has shown that over the initial two years especially, PD is equal, if not superior, to haemodialysis in terms of quality of life, morbidity and mortality (Mehrotra 2005). These findings make the balanced presentation of treatment option information and consistent delivery of education components imperative.

These belief foundations potentially prejudice the delivery of information and the framing of treatment choices, negating the individual's ability to make an informed decision. Mehrotra et al (2005) explored the association between patient education and access to self-care modalities, and found that a lack of pre-dialysis education and its limitation to planned start patients resulted in limited availability of self-care dialysis and delayed access to transplantation. Gomez et al (1999) found the delivery of a standard information pack, increased patient haemodialysis knowledge significantly (HD pre-informed knowledge 2.56 versus post-informed knowledge 4.31 $P<0.0001$). However, peritoneal dialysis remained less well understood (PD pre-informed knowledge 1.91 versus post-informed knowledge 4.04 $P<0.0069$). Mehrotra et al (2005) concur and go on to identify selection of PD as significantly associated with specific PD information presentation (OR 0.07, 95% CI 0.02 to 0.21; $P=0.0001$) and more time (2 hours) spent discussing treatment options (OR 0.06, 95% CI 0.01 to 0.28; $P=0.002$).

Mehrotra et al (2005) surmised that physician prejudice, socio-cultural contraindications, lack of infrastructure and lack of physician training, experience and confidence, were likely causes of poor PD utilization rates. However, pre-dialysis education, young ages, employment status, higher haemoglobin count and albumin level, were directly associated with increased probability of a decision in favour of PD. One potential explanation for this is the exemplar decision-making approach, based on a set of perceived 'ideal' patient characteristics, predominant in medical decision-making. This may influence doctors' delivery of treatment option information.

The most appropriate individuals to deliver education and facilitate informed decision-making, therefore requires careful consideration during intervention development. However, one must also question whether the individuals who do decide to self-care, have greater established self-efficacy, and as such, seek out information independent of that supplied.

Paterson's (2001), examined self-care decision-making and found it to be achieved through collaborative partnerships between patients and respectful HCPs. However, for many patients the reality was that professionals tended to discount experiential knowledge and have an expectation of concordance with proffered advice. Professionals further maintained this power base, as they tended to establish the agenda. The tendency of professionals to rely on objective data to determine health status was found to negate the patients' experiential insight. This raises issue in relation to staff training needs in the development of educational interventions that utilise new approaches to practice.

Patient Beliefs

Individuals' treatment decision-making and the reasons for non-selection of self-care dialysis as a modality option have been explored (McLaughlin et al 2003). Lack of satisfactory treatment explanation was reported by 60% of patients and presented the main knowledge barrier to self-care; again raising the issue of type and timing of educational interventions. The study found the most significant attitude barriers for patients were: that patients felt they should not be dialysed without medical supervision (adjusted OR 1.14, 1.05 to 1.24; $P<0.01$), fear of inadequate dialysis and fear of social isolation (adjusted OR 3.36, 1.32 to 8.49; $P<0.05$). Further barriers included: needle phobia and lack of storage space for PD supplies. These issues, it is argued, require careful consideration when creating an educational intervention designed to give patients an informed choice (McLaughlin et al 2003).

Patient and staff involvement in treatment decision-making was explored by Starzomski (1986). Patients involved in a structured pre-dialysis education programme were found to be more involved in treatment decision-making. The information needs of patients' throughout their renal journey have been identified in Ormandy's (2008) systematic review as: CKD information, renal replacement therapy, symptoms & body image. Added to these are complications of disease and treatment, family & social life, work & finance, diet & fluids, medication, test & blood results, psychological impact, other patients experience and patient organisations. The findings draw attention to the need for on-going educational phases, that include face-to-face,

individual and family sessions, written information, the opportunity for peer contact, and vicarious learning and a partnership based on mutual respect. These recommendations incorporate the elements of self-efficacy theory-based education.

Though the need for early referral and education of pre-dialysis patients and acute patients has been identified (NSF for Renal: Part One 2004a), choice is a cognitive skill and as such has great bearing on the timing of pre-dialysis education. Renal patients' cognition is likely to be detrimentally affected by their deteriorating biochemistry, inherent in the later stages of renal failure and the acute renal failure state. Increased cognitive impairment in the pre-dialysis population has been associated with: a reduced capacity to make treatment decisions; a reduction in self-care dialysis selection and a reduced time to dialysis commencement (Nulsen et al, 2008). The need for early education is therefore advocated for patients where feasible. Late referral to a nephrologist is deemed to have the greatest impact on modality selection, resulting in patients usually starting on HD (NICE 2008). This has, to a substantial degree, been reduced with the introduction of e-GFR reporting (2007) into primary physician practices, as part of the QOF (DoH 2006c); however this does not necessarily translate into increased pre-dialysis education provision. This vulnerable group will have differing individual needs and require an on-going tailored educational intervention approach.

Information Quality

With the emphasis of self-care interventions, being on the education of patients, to facilitate informed decision-making, it is important to identify the contextual factors influencing patient choice. Wuerth et al (2002) identified specific factors leading to modality selection. With ever-increasing demands upon dialysis services and limited haemodialysis capacity, the need to increase peritoneal dialysis uptake is critical. However, patient choice, as an underlying principle, needs to be maintained. Wuerth et al (2002), found patients were more likely to select self-care dialysis if they received structured pre-dialysis education. All of the PD patients (n=20) in the study actively chose their modality. By comparison, only 40% (n=8) of haemodialysis patients reported having a choice of modality. Education material, it is argued needs to be objective and include family, and staff need encouragement to support educational interventions. Influential factors reported include; patients initially being too poorly or critically ill to be able to choose a modality. These finding highlight that when individuals are too poorly to decide on a treatment option for themselves, that haemodialysis is commenced and the potential for alternative self-care options fails to be revisited.

To provide patients with true modality choice, the need for early assessment and education is identified (Mendelssohn et al 2001, Wuerth et al 2002). However, Wuerth et al suggest that non-medical reasons, such as patient autonomy, treatment flexibility and professional care, are primary in the decision-making process. Namely, late referral and lack of pre-dialysis education are argued to result in the inability of the patient to decide on self-care dialysis.

Information Impact

Pre-dialysis education has been found to result in informed treatment decision-making, and, ultimately, an increase in self-care dialysis selection (Mehrotra et al 2005). This impact on patient satisfaction and quality of life was positive. In addition, Mehrotra et al found modality selection cannot be predicted by clinical characteristics. Therefore, the imperative is for balanced delivery of pre-dialysis education and complete presentation of modality options. The authors additionally highlight the implications for financial saving, as PD offers a more economic option. However, a confounding factor was exposed by Gomez et al (1999). Despite unbiased delivery of pre-dialysis education haemodialysis knowledge was found to increase more than peritoneal dialysis knowledge. The difficulty in comprehending the complexities of peritoneal dialysis treatment is postulated as problematic, and the study recommends simpler clear diagrammatic explanations of PD.

Between 33 to 50% of the chronic kidney disease population have been identified as non-concordant with their recommended treatment regimes (Costantini et al 2006). With increased concordance cited as a potential outcome of educational interventions (Ramsdell & Annis 1996), one could surmise that because individuals have the necessary knowledge to make informed decisions; this can lead to an active decision by patients to act in accordance with recommendations. Decision-making and concordance are therefore inextricably linked. With the right information and education, an informed choice can be facilitated. However, this does raise the issue of

needing to recognise when individuals' choose not to act in accordance with advice, but do however attainment their desired outcome.

One could argue the need for a fundamental shift in both medical and nursing training, from a purely biomedical approach to a greater degree of patient-centred practice. In looking to the future for self-management, Curtin & Mapes (2005), whilst in favour of the Expert Patient Programme (2001), recognises the need for development and trialling of a comprehensive and systematic renal-specific self-management programme.

Renal Outcome

Pre-dialysis patient education resulting in success dialysis therapy, has been identified as resource-dependent and time-consuming (Starzomski 1986). However, this issue is countered by the reduction in emergency dialysis commencements and associated subsequent reduction in mortality rates, greater planned out-patient starts and a reduction in hospitalisation for patients involved in an education programme, as opposed to normal physician care. Self-efficacy-based interventions were found to improve treatment concordance (Chodesh 2005).

Multidisciplinary clinics impact on patients, when compared to standard nephrologists' care (Goldstein et al 2004) demonstrates significantly better biomedical markers for haemoglobin, albumin and calcium on commencement of dialysis. Significantly better survival rates are identified in

the psycho-educational intervention groups (Devins et al 2005). Inaguma et al (2006) describe the educational components and format used in the study as small group, multi-disciplinary education presentation, focussing on: renal function, treatment options, blood results, diet and welfare. The resulting effect was found to be; planned initiation of RRT, improved anaemia ($8.5\text{g/dL} \pm 1.2$ $P=0.030$) and nutritional status ($3.6\text{g/dL} \pm 3.6$, $P=0.001$) with a net reduction in hospitalisation, and, ultimately, reduced financial cost (Inaguma et al 2006). The study clearly identifies the effect of improved patient status at commencement of dialysis and the benefit of multidisciplinary input.

Despite one study delivering a psychosocial education intervention, no psychosocial outcomes are identified (Devins et al 2005). However, Devins et al's longer 20-year follow-up provides important findings not revealed by other authors. Though early or late referral to a nephrologist was found not to influence participant survival, participation in the psycho-educational intervention was found to promote self-management and self-efficacy, and delay time to dialysis initiation. Analysis of data by intention to treat strengthens the validity of the findings (Devins et al 2005).

The perspective of patients engaged in active self-management of life was explored by (Curtin & Mapes 2001), and they identify an overarching theme of patient/professional partnerships and interaction with the healthcare system, which was crucial in attaining self-management. This raises the issue of divergent perspectives. If doctors, as the authors suggest, do not perceive themselves to be influential in their patients' treatment decision-

making, potentially they could fail to provide a relationship conducive to patient self-management. Doctors need to be aware of their importance in the doctor/patient relationship, and the influential position they hold if they are to provide the level of support individuals require to feel confident to self-manage. An interesting point of note is the complete absence of diabetes as a co-morbid factor in this cohort. The patient population is therefore somewhat atypical, given the known diabetic co-morbidity level of 25% in the CKD populations (Renal Registry 2009), and must be recognised when considering the findings in relation to the creation of a pre-dialysis educational intervention. These findings lay some of the groundwork for the development of a self-management intervention designed for pre-dialysis patients (Curtin & Mapes 2001).

Alongside early referral to nephrology services and multidisciplinary input, structured pre-dialysis education is argued to be central to improved patient outcome at commencement of dialysis (Goldstein et al 2004, Inaguma et al 2006). The need for effective pre-dialysis planning and education is therefore evident (Wuerth et al 2002), especially since knowledge and ability to self-manage was found to be significantly associated with improved patient functioning and well-being.

Limitations in the Renal Literature

There is a lack of validated outcome measures and use of inappropriate measures illustrated across the systematic review articles and the wider renal literature. This raises issues in relation to the validity of the literature review findings. This is further compounded by concerns about methodology and poor reporting of; randomisation, blinding, dropout rates. Loss to follow up reporting is weak as are the power calculations and intention to treat analysis.

A lot of uncertainty remains about the role of the evidence presented in the literature review studies. The heterogeneous nature of the studies included, restricts the ability to synthesise outcome data. Studies of renal patient educational interventions lack clear descriptions of the study design, methodology and analysis, making overall synthesis of the data and the drawing of conclusions problematic. The study limitations include: small sample size; short follow-up in all but one study; lack of a theoretical foundation for educational interventions; lack of component/intervention detail; lack of cost-effectiveness reporting; and sub-optimal trial design. Study reliability is limited by ambiguous reporting, the failure to report intervention impact, the lack of baseline data and lack of power analysis.

The renal studies lack validated outcome measures relating to cognitive, effective attitudinal and behavioural change, but these would greatly add to the validity and applicability of defined interventions. However, these studies

do paint a picture of the patient and the pre-dialysis context, and various factors impacting upon the individual. For this reason the results are worthy of careful consideration in the formulation of an educational intervention for pre-dialysis patients.

Summary of Renal Literature Review Recommendations

The literature review findings show the necessity for early CKD, interventions to be based on increasing renal knowledge and improving concordance with treatment and life-style advice. In the pre-dialysis cohort these elements are developed further to incorporate knowledge of dialysis and renal failure, and managing renal failure by developing decision-making, self-care and coping skills. Educational interventions are recommended to include both informative and psychological components (Mason et al 2008). Mason et al argue that future research must have: a strong theoretical framework; an educational intervention that is practical and well designed which engages patients and is cost-effective; consistent intervention delivery to aid implementation and evaluation; and rigorous evaluation of effectiveness. Further findings go on to recommend the development of knowledge and psychological questionnaires/tools specifically for use in the renal population. On the basis of the findings presented it could be argued that a renal-specific decision-making tool incorporated into educational interventions may improve uptake of self-care therapies.

The data from the renal studies has been synthesised and recommendations include: development of patient-centred care, which incorporates active

patient/healthcare professional partnerships, to increase successful management of chronic renal disease (Costantini 2006, Curtin & Mapes 2001). Increased education of both patients and professionals will help to ensure early referral to nephrology services (Lenz et al 2005). Psycho-educational interventions have been found to achieve a meaningful delay in treatment commencement (Devins et al 2005, Krespi et al 2004). Multidisciplinary intervention delivery has shown improved clinical outcomes and reduced hospitalisation and mortality (Goldstein et al 2004). Furthermore, it has been shown to reduce patients' negative pre-dialysis beliefs and has improved quality of life.

A standard information pack, including clear PD diagrams, was found to help increase PD treatment option understanding (Gomez et al 1999). Structured education needs to be provided, so people with long-term conditions can self-manage and be involved in treatment decision-making (Singh 2005). Patient education is needed to optimise self-care treatment up-take. Incorporation of support for self-efficacy within a patient-centred, flexible education intervention should include: verbal, visual and vicarious education delivery. These elements can improve patients' treatment knowledge (Iles-Smith 2005). Self-efficacy-enhancing educational interventions are advocated to boost self-management behaviours (Aujoulet et al 2007). Successful interventions increased knowledge and self-efficacy, and were typically healthcare professional-led, provided education supported by written information and were delivered in small groups over a number of weeks (Berzins 2009). Face-to-face interventions were found to be the most

effective format for the delivery of self-management programmes (Warsi et al 2004).

Descriptive meta-analysis data suggests that enhanced educational methods or a combination of affective, cognitive and behavioural therapies produce a bigger effect than didactic or psycho-educational interventions (Cooper et al 2001). Self-management approaches were found to be as effective as cognitive-behavioural approaches and improved patient knowledge, self-efficacy, self-management behaviours and health status aspects (Barlow et al 2002).

Educational interventions need to be delivered regularly to facilitate optimal timing of attendance (Inaguma et al 2006). However, frequency and contact time elicit no consistent patterns in the outcomes (Cooper 2001). The aim of interventions should be to improve knowledge, skills and attitudes to self-care (McLaughlin et al 2003, Mendelssohn 2005). The use of simple repetitive educations has been found to engage patients, develop patient/professional relationships and improve knowledge retention (Ramsdell & Annis 1996). Education delivery is advised one year before treatment commencement and should include the patient and family. It should also include vicarious learning of treatment options (Lenz et al 2005). Management programmes for chronic disease have resulted in clinically and statistically significant outcomes for older adults (Chodesh et al 2005).

Objective written information helped to overcome potential treatment bias and should be adapted for acute-start patient needs (Wuerth et al 2002). Written information pertaining to treatment choices should be incorporated

into educational interventions and include decision-making tools to increase self-management selection.

Patient Decision Aids have been shown to improve patient knowledge, decision quality, decision process, feeling informed and clear about values. More complex decision aids incorporating probability data were found to be more effective than simple ones (O'Connor et al 2007)

The key recommendation raised by Mason et al's systematic review was the need for a robust theoretical research framework. The MRC's (2000) Complex Interventions Framework, it is suggested provides such a guide for research design and methods. Utilisation of the Complex Intervention Framework, based on the recommendation from Mason et al's systematic review, is discussed at the end of this chapter. Use of a consistent approach in educational intervention studies will aid validity and generalisability of results, and allow studies to build upon previous findings.

Conclusion

Individuals with non-reversible renal decline are in a unique position within long-term condition health care. The pre-dialysis journey involves decision-making about renal replacement treatment, which will extend their lifespan. The treatment options have extensive, life-long implications for individuals, and will fundamentally change their lifestyle. The long-term condition and renal literature has identified elements that are effective in self-management education, and which aid patient decision-making. Self-efficacy theory is

predominant in the literature and underpins the development of self-management interventions. Theory-based interventions improve knowledge, self-efficacy and self-management, resulting in improved clinical outcome measures.

The use of written information, individualised and group education delivery, again increases knowledge and self-efficacy and has significantly improved HbA1c in individuals with diabetes, and blood pressure in people with hypertension. However, these studies lacked follow-up beyond two years, hence the long-term impact cannot be identified. Patients' decision-making quality and decision-making process was improved with the incorporation of decision aids into educational interventions. However, this leaves a number of questions unanswered.

In order to explore the questions raised by the literature review effectively, this study will be guided by the MRC Complex Intervention Framework, as recommended by Mason et al (2008).

MRC Complex Intervention Framework

The Complex Intervention Framework was developed by the Medical Research Council (MRC Framework 2000) to guide the design of complex interventions to improve health. The complex nature of pre-dialysis recipients' healthcare needs has been identified by the literature review. Consequently their education and informed treatment decision-making needs, will require the inclusion of multiple aspects, combined to provide a comprehensive complex package of care and these include; intervention components, intervention behaviours, intervention delivery and a diverse target audiences. The MRC Framework is ideally placed to guide the development of a theory based, pre-dialysis educational intervention study.

Complex interventions provide a challenge to researchers, in their development, reporting, implementation and evaluation, by the sheer volume and diversity of influential dynamics. The creation of the MRC Complex Intervention Framework (MRC 2000) ultimately aims to guide and standardise the development and evaluation of such interventions. Table

2.0.6

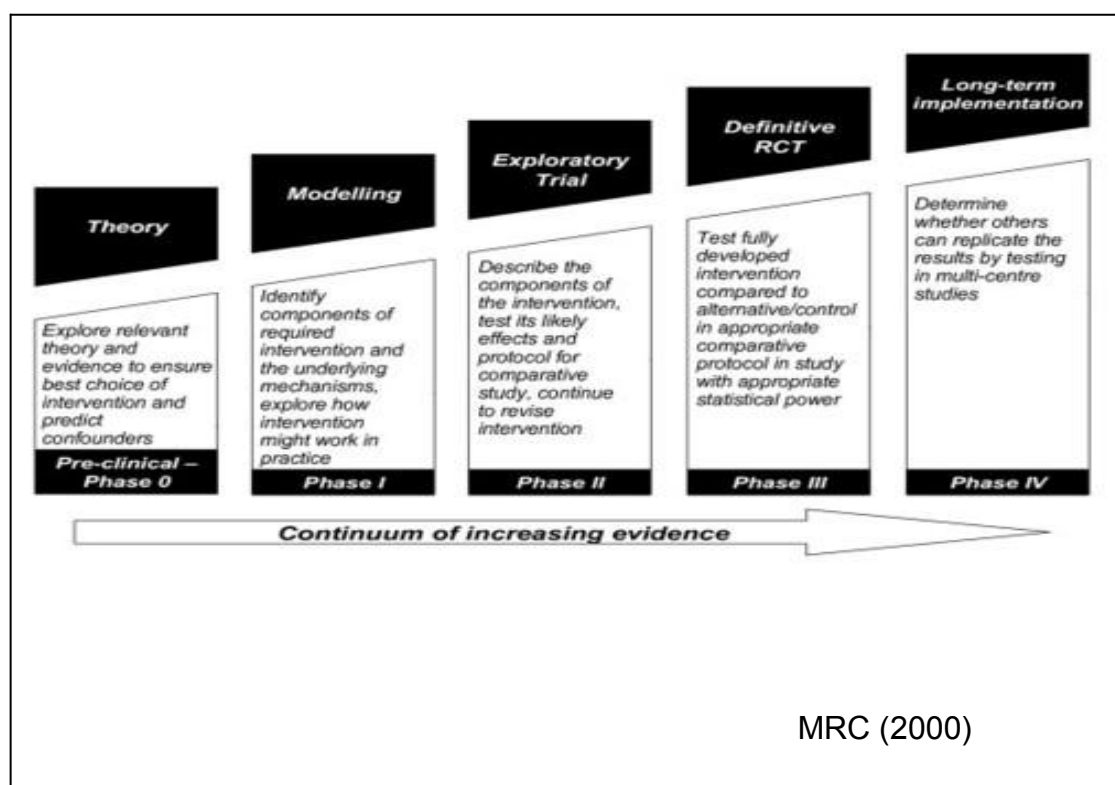


Table 2.0.6 Complex Intervention Framework

Theory Phase

The Theory Phase will help to establish the theoretical justification for a complex pre-dialysis educational intervention. A systematic review of the self-management, renal education and decision-making literature, has failed to identify practice sufficiently and therefore findings will be supplemented with a Needs Assessment Study (Chapter 3).

The theory and evidence ascertained at this stage will be used to establish investigation need and will influence intervention design. The combining of phases, or a cyclical return to the theory phase, is advocated, adds greater flexibility of approach to trial design, and seeks to enhance clearer definition of the research process (MRC 2000).

Identification of the pre-dialysis educational context will help to identify barriers and rule out previously tested, unhelpful educational factors. Needs assessment research appears essential as the evidence pertaining to theory-based pre-dialysis educational interventions is lacking, in both quality and quantity. Extensive analysis of influential factors should lead to greater specificity in design and methodology by informing the theoretical basis, hypotheses and the specific components involved (Campbell et al 2000).

Greater contextual understanding of the educational components patients find beneficial in making treatment decisions can inform methodological design. The knowledge and skills they felt they needed to optimise their pre-dialysis health status will enhance insight. The Theory Phase will be informed by the literature review and patient needs assessment. The subsequent Modelling Phase, informed by the theory phase findings, will explore; trial design, potential component selection and component inter-relationships.

Modelling Phase

The Modelling Phase proceeds from understanding the intervention, to the prediction of possible effects, as key components and their inter-relationship are identified. Qualitative testing in the form of focus groups, surveys, observational studies and case studies is advocated (MRC 2000). Qualitative methodologies will be employed to identify and trial the pre-dialysis educational components available in order to explore individuals' experience of the intervention. The qualitative methodology aims to explore the following areas of interest concerning Pre-Dialysis Educational Interventions:

Regarding pre-dialysis education:

- Who should deliver it?
- What intervention components should be delivered?
- How should components be delivered?

Regarding individuals' confidence to deal with the pre-dialysis journey:

- What influences individuals' self-efficacy?
- What helps them to cope and adjust over the pre-dialysis period?

With regards to pre-dialysis educational intervention:

- What should a learning theory and health policy-informed pre-dialysis education intervention comprise?
- How does it affect individuals' decision-making about dialysis treatment choice?

Importantly, this phase allows potential barriers to be identified, so that ways to overcome them can be considered and applied (Campbell 2000). This aids the standardisation of intervention content and delivery; an issue frequently identified as a weakness in complex intervention trials (MRC 2000). Consideration of the intervention as a whole will ultimately inform strategies employed in an Exploratory Phase trial and beyond. The Theory Phase groundwork in this study aims to identify who the intervention will work for, how it will work, what effect it is likely to have and where unmet need still exists. The Modelling Phase continues this development to identify and trial educational components through PAR and explore participants' experience

and treatment decision-making through serialised interviews over the pre-dialysis journey.

Complex Intervention Critical Analysis

Bradley et al (1999) argue the importance of not only evaluating complex intervention outcomes but also the need to understand how the process is applied, so that replication of studies can be successful. Hence, the overall effectiveness of the pre-dialysis intervention and the means by which it was achieved will be considered. Such explicit description facilitates replication and further validation then becomes possible. The need to include complex interventions in systematic review evidence, Mulhauser & Berger (2002) and Sturt (2006) argue, requires considered and evaluation.

Hawe et al (2004), discusses the need for functional, as opposed to compositional definition of complex interventions. This it is argued would facilitate the adaptation of interventions to differing contextual situations. This is of particular importance as the renal patient population is diverse, in terms of ethnicity and culture, and geographical location and the local population will influence these demographics. The need to standardise pre-dialysis education intervention function, so that the form can be adapted and variable is crucial for generalisability and functional application. Hawe et al (2004), recommends reversing current trial design custom to identify and understand the research community first, thus identifying local need and adopting trial design to fit.

The iterative process and flexibility of approach to trial design facilitated by the MRC Framework will enhance clearer definition of the research process. The theory phase will allow synthesis of literature from the review and Needs Assessment Study and if necessary alteration of hypothesis on the basis of the findings (Campbell et al 2000). The revised MRC Framework (2008) suggests that though it is important to understand processes, the outcome evaluation remains the fundamental imperative; tailoring to local circumstances as opposed to complete standardisation, may be beneficial; to facilitate the synthesis of evidence, enable replication and increased scope for implementation, interventions should be described in detail (MRC 2008).

Conclusion

The MRC's complex intervention framework provides a structure within which to create and investigate multi-component pre-dialysis education and treatment decision-making research. The continuing development of complex intervention analysis and a growing interest in its influence and utilisation are identified (MRC 2008). The guidelines are designed to enable appropriate methodological and practical choices to be made not only by researchers, but also by their funders, policy makers and journal editors (MRC 2008).

The overall aim of the research presented is to develop and explore the impact of pre-dialysis educational interventions. Therefore, the MRC Framework (2000) provides the overarching study framework. The research will address the first two phases of the MRC Framework. The Theory building and Modelling Phases, and these are essentially qualitative.

Reviewing the findings of existing renal and long-term condition literature has begun to build a knowledge base. To answer these questions it is important to establish the Theoretical Phase foundations within the Complex Intervention Framework for study development (MRC 2000). Qualitative exploration of the education that current dialysis patients identify as useful, in the pre-dialysis journey, will add context to the literature review findings.

Once the theoretical foundations have been established, the study will progress to the Modelling Phase of the Complex Intervention Framework. Participant Action Research will develop and deliver theory based educational components into pre-dialysis practice. The Service Users Pre-Dialysis and Treatment Decision-Making Experience: A Grounded Theory Study will explore the educational and decision-making journey experienced by individuals, using an inductive research methodology.

Chapter Three:

Retrospective Patient Views of Pre-Dialysis Education: A Needs Assessment Study

Chapter Three: Retrospective Patient Views of Pre-Dialysis Education: A Needs Assessment Study

Introduction

This chapter presents the Retrospective Patient Views of Pre-Dialysis Education: A Needs Assessment Study (Needs Assessment Study) with an overview of the study methodology and methods employed. The emergent themes reported contribute insights to the theoretical phase of the MRC Framework utilised in this research. Conclusions and their implications for the next stage of the MRC Framework, the Modelling Phase, are identified. The Needs Assessment Study and literature review findings form the theoretical foundation for the development of the Participatory Action Research and the Service Users Pre-Dialysis and Treatment Decision-Making Experience (Pre-Dialysis Study) as identified in Figure 3.0.0.

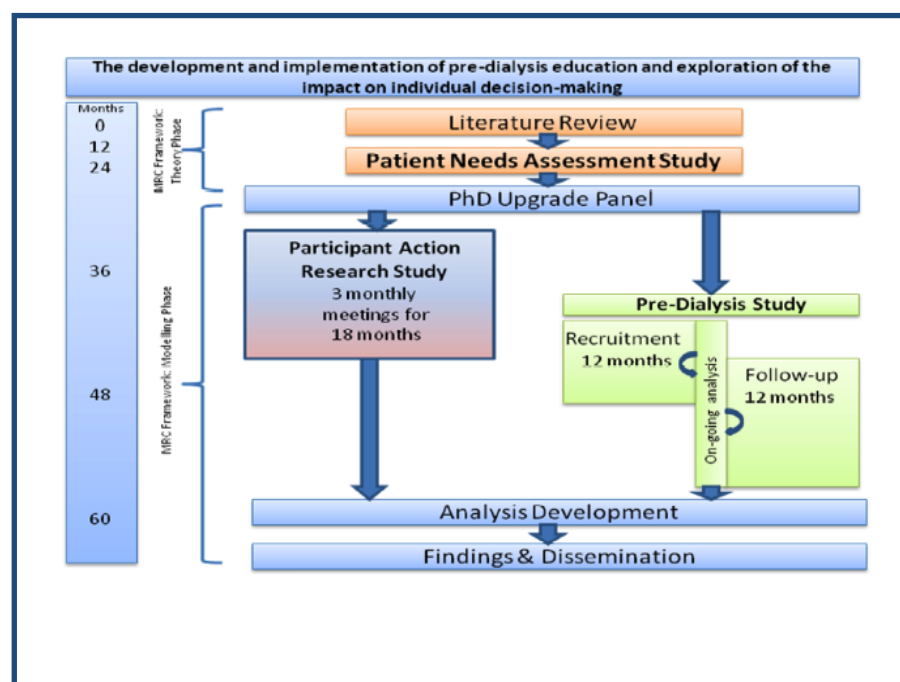


Figure 3.0.0 Study Flow Chart

Methodology

The aim of the Needs Assessment Study was to understand how people with established renal failure (ERF), made use of educational inputs they had traditionally received, to help them make decisions about treatment modality. The importance individuals gave to the various factors influencing choice of modality and treatment preferences were explored. The study sought to understand better the experiences of patients who have undergone pre-dialysis education.

Thematic Analysis (Miles & Huberman 1994) has been utilised in this study to document and understand the communication of meaning. Discovery of themes was achieved through the reflexive and iterative process of data collection, analysis and interpretation. Purposive sampling sought participants' who were representative of the wider renal cohort. Semi-structured interviews, with their roots in the interactionist tradition (Dingwall 1997), provide more focused information (Rubin & Rubin 1995). Focus is therefore upon issues related to the research question or hypothesis and organised around a set of pre-determined questions, which can be explored, clarified and probed (Whiting 2008, Rose 1994).

Thematic Analysis

Transcribed data was reduced through coding. Once transcribed the interview scripts were reviewed to increase familiarity with the data. The use of NVivo 7 qualitative data analysis software facilitated the documentation of

memos during this phase. Memos can relate to language use, context, potential categories and emergent understanding.

As a list of broad categories began to develop from the original semi-structured interview questions, so themes emerged from the data. As coding progressed, the codes produce categories and sub-categories to make sense of the themes and patterns in the participants' narrative.

The categories and emergent themes were arranged to form a matrix, and populated with the coded data. This allowed large amounts of data to be seen at once. With the coded data drawn together in a coding matrix, understanding of the pre-dialysis experience could evolve and justified conclusions were drawn.

Throughout the data collection, transcription and coding, the meaning of the pre-dialysis experience began to unfurl. The patterns, and importantly, the irregularities started to emerge. During this phase it remained imperative that alternative and competing themes were identified and explored. Alternative explanations needed to be considered, to ensure analysis credibility. As analysis progressed cognisance of continued fit with the original data and consideration of alternative conclusions was important. The secondary analysis of data by academic supervisors provided cross-examination during data analysis, coding and framework agreement thus increasing reliability and validity. The resultant framework formed the foundation for explaining participants meaning of pre-dialysis educational needs.

The research question that the study aimed to elucidate, through the subjective opinions of participants, was:

How do people with established renal failure make use of educational inputs they receive to help them make treatment decisions?

Method

Aims

The study aimed to identify:

- 1) The importance individuals give to the various factors influencing choice of modality and treatment preferences.
- 2) The experiences of patients who have undergone education about dialysis, in order to indicate potentially influential elements for dialysis education programmes. The effect patient education has on their eventual choice of dialysis modality.
- 3) The particular needs of patients who start dialysis as an emergency, who at present seem particularly disadvantaged by current education programmes, and have a particularly low rate of PD utilization.

Study Design

User Involvement

Pre-piloting sought critical feedback on all aspects of the semi-structured interview schedule, from a selection of respondents similar to, but not part, of the research group. Service users attending for haemodialysis treatment at

the study site were approached in person by the researcher. The Needs Assessment Study and the importance of pre-piloting of interview questions were explained and a Participant Information Sheet for the study was supplied. Service users showing an interest in participating were re-visited at their next treatment session. For those consenting to participate in the pre-piloting, a convenient time and location was established. The aim of engaging service users was to identify the need for changes in question wording, question context, question order, or indeed the need to remove or replace questions (Gillham 2005). As a result of three pilot interviews, prompts were added to some questions as shown in *Italics* in Table 3.0.1.

| |
|---|
| <ul style="list-style-type: none"> • What was your experience of renal services before you started dialysis? |
| <ul style="list-style-type: none"> • What choices were you given about the sort of treatment you could have? |
| <ul style="list-style-type: none"> • Who did you discuss your treatment with and how did they influence your choice? <i>(Planned) What pre-dialysis sessions if any did you attend?</i> <i>(Acute) What education have you had since starting dialysis?</i> |
| <ul style="list-style-type: none"> • Where have you got information from about renal dialysis treatment? <i>(Prompt) Staff, other patients, leaflets, DVD's, books, internet.</i> |
| <ul style="list-style-type: none"> • Which information sources have you found most effective? (Can you give an example of how a piece of information has changed the way you manage your condition?) |
| <ul style="list-style-type: none"> • What were the most important things that made you choose this type of dialysis or would affect your choice? |
| <ul style="list-style-type: none"> • What things are good and not so good about this type of dialysis? <i>(Prompt) Effect on life style and quality of life.</i> |
| <ul style="list-style-type: none"> • Have you met people having different types of dialysis and what has been your impression of the alternatives? |

| |
|---|
| <ul style="list-style-type: none"> • What do you think is important to know before you start dialysis? |
| <ul style="list-style-type: none"> • What education do you think people need once they have started dialysis? |
| <ul style="list-style-type: none"> • What sort of education sessions would you find most useful (Prompt) Taught sessions, DVD's, Internet (with or without support) Group or individual, location, time, whilst on dialysis. |

Table 3.0.1 Interview Schedule and Question Prompts

The semi-structured interview schedule was designed to elicit an understanding of how the interviewees frame and make sense of, their pre-dialysis educational experiences and influences on their treatment decision-making, without stifling responses. Interviews were audio recorded and transcribed verbatim by the researcher.

Sampling

Participants were selected through a purposive sampling approach to meet a number of specific objectives (1) those with a recent pre-dialysis education perspective in the 3-6 month group, (2) the experience of hindsight on analysis of renal education need in the 2-3 year group responses, (3) participants who started in a planned manner, (4) participants who started in an unplanned manner. Though purposive sampling means result of the research cannot be generalised to a population (Bryman 2008), it did facilitate the recruitment of varied participants that add different characteristics to the data. Sampling participants with different amount of dialysis experience and both types of dialysis modality sought a broad range of views and opinions.

Population

A total of 29 patients were recruited from the study sites dialysis population. The initial proposal indicated that 40 patients, ten from each of the following groups would be recruited. It was the opinion of the ethics committee that data saturation would most probably be reached prior to recruitment of the stated numbers. This proved to be so and the group sizes are indicative of the point at which data saturation was able to confer validity and trustworthiness to findings as no new themes were being detected.

Individuals were invited to participate by the researcher, following attendance at their routine renal clinic appointments. Eligible patients were 18 years of age or over and the patient's informed consent to participate in the study was undertaken prior to interview delivery. The patients had commenced dialysis within the past 3-6 months or 2-3 years respectively. Exclusion criteria were therefore those aged below 18 years of age, unable to give informed consent and those who had not commenced dialysis within the stipulated time period.

Data Collection

Data were collected between July 2007 and February 2008. Individuals were provided with a participant information sheet, a consent to participate form, the researchers contact details and informed consent was completed. Written consent was completed immediately prior to participant interviews.

Interviews were conducted whilst the patient was dialysing or in the researchers office and ranged from 30-60 minutes. The researcher audio

recorded interviews with the participants' consent. Field notes, where appropriate, were made after interview completion so the researcher's attention was focused on the interviewee throughout. Interviews were fully transcribed, as soon as possible, following the interview to maintain clarity of understanding and nuance. Participants were offered a copy of the transcript for review. The overarching ethical principles applied are identified in the methods chapter (p 225).

Thematic Analysis

Transcription followed the first interview and data were open-coded. Thematic analysis reduced the data through coding. Broad categories and emergent themes were identified to facilitate the comparison of similar and divergent variables, based on data emerging from interviews. Analysis produced insightful data resulting in a coding matrix of categories, sub-categories and emerging analytic themes (Appendix 6).

Validity & Reliability

Validity in thematic analysis lies in the fair representation of the pre-dialysis experience, which can be achieved by ensuring the results are developed from the data collected. Secondary data analysis of the first three interviews was undertaken by two academic supervisors to challenge analysis and interpretation. The extensive experience of the secondary coders highlighted additional nuances in participants' responses and resulted in continued development of the coding framework and the researchers' understanding. Analysis of data attracting the same codes, aimed to challenge the

developing codes and assess the need for new ones or sub-codes, until the developed coding and themes fit all of the data. Awareness of interpretation bias and reliability testing through identification of the consistent application of the coding themes by three separate coders helped to minimise the effect. Inclusion of narrative data was crucial, as quotes and responses confirm or refute the explanations being derived. The coding framework is presented in Appendix 6.

Results

The range of interview questions employed, allowed a detailed exploration of pre-dialysis education and the contextual factors surrounding it, from the patients' perspective. This enabled a depth of description to emerge, from the qualitative data, and resulted in an increased understanding of the education issues relevant to the participants.

A sample size of 29 participant interviews was found to be sufficient to attain data saturation (Guest et al 2006). Participant demographics are identified in Table 3.0.2 and closely reflect the national averages for age, gender ratios and haemodialysis treatment choice and shown in italics (Renal Registry 2009).

| | | | | |
|---|----------------------|---------------|----------------------------|-----------|
| Age | | Mean 64 years | | |
| Gender | Male | 65%, n=19 | Female | 35%, n=10 |
| Type of Treatment | Haemodialysis | 72%, n=21 | Peritoneal Dialysis | 28%, n=8 |
| Time since commencement of treatment | 3-6 months | n=15 | 2-3 years | n=14 |
| Treatment start conditions | Planned start | 72%, n=21 | Unplanned start | 28%, n=8 |

Table 3.0.2 Participant Demographics & Treatment Statistics

The newly started (3-6 months), and the established patients (2-3 years), were recruited to bring a diversity of experience, and varying degrees of hindsight, to the experiences expressed.

Educational Input Prior to the PAR Study

At the time of Needs Assessment Study information delivery and treatment decision-making was facilitated by 5 nephrologists and 1 CNS. With vague non-prescriptive pre-dialysis education guidelines, as discussed in Chapter Two (p 50), information delivery was diverse and ad-hoc, and influenced by the vagaries of the nephrologists. Most individuals' received the 'Help I've got kidney failure' booklet (Higgins 2005) and verbal information from the nephrologists, though some were referred to the CNS. The CNS provided one-to-one treatment information to facilitate informed decision-making. The original Education Day (p298) was only available to service users seen at

UHCW clinics and not those seen in outlying clinics. Additionally, not all nephrologists referred patients to the Education Day. The disparate nature of information delivery reveals the lack of any behavioural, educational or decision-making theoretical foundation.

The results explore participants' views and opinions of pre-dialysis education and the similarities and disparities emerging. Categories are illustrated and supported by patients' expressed experiences to illustrate the properties and context associated with each category. Five main categories were identified from the data:

- Decision-making and information mediation through relationships
- Modes of information delivery
- Influences on patients' cognitive functioning
- Patients' decision-making criteria
- Outcomes of decision-making

Though distinct in their presentation here, in reality they represent varying levels of influence and overlap for the individual participants interviewed. The dilemmas and decision-making issues participants are confronted with are reflected in their relationships with HCPs. The education they found useful and the effect of ESRF on the decision-making experience. The main themes identified during data analysis are presented in the following section.

Decision-Making and Information Mediation through Relationships

Relationships between individuals with ERF and healthcare professionals play a key role in the treatment decision-making process. Respondents who mentioned nephrology consultants and clinical nurse specialists (CNS) cited them as positive and beneficial information sources. One participant voices requirements patients may have of their consultation:

“Well I find my consultant has been good, a good supply of information really and it's very important that they give you what you want to know. They don't rush you out of the office.”

Female, Aged 66

Emphasis is on the need to be given time and the information that they find pertinent, thus allowing risk benefit analysis to be employed. Another individual exemplifies the perception of the CNS's input:

“I used to see X (CNS). She was very good, very positive and supportive”.

Male, Aged 65

The element of support comes through far more strongly in the patients' experiences with the CNS. However, participants' expectations regarding the trustworthiness of information provided by others, including healthcare professionals (HCPs), relates to pre-conceptions about the relative roles and authority possessed by doctors and nurses, as one participant questions:

“What you get from the hospital from the nurses, you presume they know what they are talking about... They seem very knowledgeable. Quite a good set up they’ve got”.

Male, Aged 72

Further influence came from their experiences of other people with renal problems. Participants’ experience of planned expert patient contact resulted in positive impacts. Benefits of such vicarious learning are upon improved treatment understanding and the allaying of fears, as this individual expressed:

“I was scared stiff of needles...She [ward sister] said would you like to go into the dialysis unit and see what actually goes on? I can take you...He [patient] was on dialysis and we had a look at the needles in his arm, he talked to us about what it entails and told us about it. So that was educational. That was good”.

Male, Aged 61

The potential to positively impact patients’ confidence about informed decision-making are evidenced. Conversely, unplanned contact was with other people in hospital who were admitted with dialysis-related problems and resulted in negative impacts. When asked about patient contact one participant stated:

“Well when I’ve been an in-patient on the ward you see lots of problems with dialysis... I probably had a bad impression”.

Female, Aged 84

Such experiences have the potential to influence future decision-making treatment choices negatively.

Modes of information delivery

Preference for information delivery varied with individual learning style and fluctuated depending on participants' health status. These variations included, written versus verbal presentation and individual versus group presentation.

Need for written information was widely cited by participants. Essential factors indicated were brevity, ease of reading, illustrations, treatment pros and cons, treatment options over time and use of the information for repeated and on-going reference. One individual typifies the value of being able to read and then re-read given information:

“You know I read it quite a few times. It gave me all the different types of dialysis and what it involves. It was quite informative really”

Female, Aged 42

Another brings to light:

“By the time you get out of here you can't remember half the things. At least if you have got it written down you can go back to it”

Male, Aged 65

This use as reference material was echoed time and again by individuals. This indicates the importance of not only being supplied with appropriate information, that is neutrally framed, but also the ability to take it away and utilise it as reference material, share it with others and to back up verbal educative communication. Key to this however, is consideration of the detrimental effect of uraemia on individuals' cognitive functioning, their reduced capacity to recall or learn and therefore the increased importance of reference material.

Group presentation was considered by some to facilitate sharing of experiences, learning from other individuals' questions and challenging information with peer support. A desire to generate knowledge through questioning is expressed by one individual:

"I don't mind a group; often some person will mention something or ask some question on something I hadn't thought about, which from the answer given you find helpful. A group I feel is often better than on an individual basis" another believed "I think groups are more supportive".

Female, Aged 84

Identifying the benefits gained from other individuals' questions and support and highlights issues hitherto unconsidered by individuals. Interestingly only a minority of female participants mentioned the benefit of a support network. One could interpret this as the patients' lack of a perceived link between health, quality of life and social support. The down side of a group approach

was expressed as lack of attention to personal needs, as stated by one individual, whose recognises her preference:

“I think probably seeing someone individually because I have other complications, it’s the personal things I want to ask about that relates to me and other things I’ve got”.

Female, Aged 61

Experience and the expert status of this self-caring individual with diabetes, add further contextual influences to their view of the educative process. It’s about how the information fits with their values, self-management experience and co-morbidities. A further dimension pertaining to the flexibility of approach has been reflected in an unplanned start participant’s response:

“I think when you first start you need one-to-one; it would probably be better”.

Male, Aged 46

Timing of education was indicated as an issue and this was influenced by the fear and anxiety associated with a potentially life threatening, unplanned start status and compounded by uraemia.

Influences on patients’ cognitive functioning

Advanced age, and more specifically advanced disease progression resulting in uraemia, negatively impacted participants’ cognitive functioning and consequently their ability to make informed decisions. An acute start

participant expresses the salience of recognising the effect of uraemia, on the individual's capacity to learn and absorb new information:

"When I was took ill it's very hard to remember it all, I was very poorly and just couldn't remember things. It's very difficult to take things in. That has improved".

Female, Aged 64

Not only are the issues associated with uraemia and its detrimental effect on mental capacity illuminated by the data, but the disordered thinking and altered ability to cope in a crisis situations. Crucially the fluctuating levels of learning ability were associated with fluctuating levels of wellness.

When discussing the degree of information required for making an informed treatment decision, one participant expressed complete confidence and faith in the healthcare professionals and their actions in individuals' best interests, stating:

"I don't understand all the words they use and I don't try to remember them. When you get to my age its better if you don't...Nothing except that what they are doing for you is the best. I didn't need to know anything".

Male, Aged 76

Participants' psychological state, especially fear, affected the degree of control participants wished to assume, or abdicate, to healthcare professionals or carers regarding their treatment decision. Preference for information varied

greatly with some participants preferring to 'take it as it comes'. The filtering out of certain types of information and not knowing 'too much' seem to provide a coping mechanism for some participants as this individual expressed:

"As far as the actual technical stuff that lies behind all that I don't particularly want to know it. Creatinine levels and one thing and another, as long as you know you're doing okay, you're doing okay. I'd just go along with it and know what I need to know and what the consultants tell me. There is no need to go in-depth really. I'm quite happy with that, if I wanted to know I would talk to a consultant".

Female, Aged 66

Though this individual cites concordance with medical advice, discord may arise when avoidance or detachment is employed and the full implications of treatment options become apparent.

Patients' decision-making criteria

Key decision-criteria were found to override other considerations when making treatment choices. Key criteria included the fear of; hospitals, infections, needles, blood and loss of control and autonomy. It is important to note that the examples from the data are, in all but one case, negative and associated with patients' fears. These issues are compounded by a lack of confidence to self-care. Illustrating the considerations required when making an informed modality choice one participant stated:

“I think it is more clinical for me to come here and get the professionals on it, get it all done right. You see at home you could get infections but here you shouldn't do because everything is done and how it's meant to be”.

Male, Aged 52

The expressed preference, justified on the basis of professional care provision and cleanliness, highlights the participants risk benefit analysis. This reasoning may however belie a lack of confidence to self-care.

The diverse variety of decision-making foundations are clearly recognized by another participant:

“I think the first time I was with the consultant. I realised fairly quickly that I was going to be having dialysis for the foreseeable future. My reaction was I want CAPD...My instinct was to choose CAPD... I made the decision very quickly that I was going to do CAPD...I hate hospitals”.

Male, Aged 46

This rapid heuristic decision-making was based upon his dislike of hospitals and for this man it was the key criterion over-riding and negating other considerations. Core values and risk benefit analysis or their absence may determine the efficacy of the decision made. Conversely, another participant states:

“I really thought it would be easier if I could do it at home; I particularly wanted to have the control”.

Female, Aged 61

This established and well-controlled diabetic, who is already experienced and efficacious in self-management, illustrates the desire to self-care in the home environment. Her positive value-based decision-making criteria are associated with maintenance of autonomy. For those participants opting for PD all were aware of the treatment choices. However, of those respondents who mentioned treatment choice half had been advised to have PD.

One participant illustrates the potential for clinician-influenced decision-making:

“Choices?... I did have a good choice; there was a choice of two treatments. The haemo, haemodialysis and the other one (points at the abdomen)... So he [consultant] said that he thinks this one would suit me better [haemodialysis] and I thought the same so I went for that”.

Female, Aged 47

This individual describes having two good choices, but interestingly is unable to verbalise peritoneal dialysis. The decision-making process is defined by the consultant's opinion and the patient's concurrence. The lack of discussion or joint consideration is indicative of a paternalistic relationship. Of those participants given no choice of treatment and started on HD, most had contraindications. However, a couple were unaware of PD as an option, illustrating the case in point. It is not only the omission of choice, but also the

influential pressure exerted by medical expert opinion and the framing of information, that cannot be underestimated. Respondents on PD, cited lifestyle and freedom as the key criteria in selecting PD. Worthy of note is that individuals on HD cite, being alive and sociability of HD as key decision-making criteria. Therefore the health perspectives and personal values that patients bring to the decision-making process are fundamental to appropriate personal choice.

Reflective insight into the individual's own personality traits is succinctly illustrated by one patient, who opted for haemodialysis:

“There are for's and against. If you are doing that [peritoneal dialysis] there has got to be a tendency to lapse” another believes: “Sometimes I guess I would think oh I cannot be bothered to do it today. I'll do it later and later never comes...I knew I would (miss treatments), so it is self-preservation”.

Male, Aged 46

Such frank descriptions indicate a level of insight and self-awareness that are crucial factors in the decision-making process and, ultimately, preservation of health.

Outcomes of treatment decision-making

‘Decision regrets’ (O'Connor 1999), though not a common theme, were expressed, highlighting the need for explicit treatment options education, as

well as the imperative for continued support post-treatment commencement, as exemplified by this individual:

“They came in and explained, while I was on the ward. When they asked me what option I wanted. I thought at the time CAPD would be the best...the fact it's 20 minutes to half an hour at a time. I didn't realise how it would interfere with the day, until I started it...I hate it. I can't accept it, I do it but I can't accept it...I tend to clock watch, and I tend to not want to go anywhere. I haven't got the confidence to go out in the day in fact...I just found that it has altered my life completely”.

Male, Aged 76

Despite making an apparently fully informed treatment decision following education and with the support and backing of family, the full impact and reality of that decision did not become evident until treatment was commenced. Decision-making in this instance was under pressure, as an in-patient leaving limited time to reflect on options. Compounding the situation may have been the detrimental effect of uraemia on cognitive functioning. Decision regrets such as this have been found to be more intense following an action, as opposed to an omission (Kahnemann & Miller 1986). Participants on PD cited the amount of time treatment takes up as a negative issue, and the HD participants less frequently identified this, though this still reflected their uppermost concern.

Discussion

The findings of this preparatory Needs Assessment Study add to our previous understanding of renal patients and their unique decision-making position. Participants are not only making decisions about whether or not they want life-sustaining treatment but also the type of treatment, its location and their desired degree of self-care. As such, a diverse variety of factors have been found to be influential in this cohort. The study has provided a detailed account of the beliefs and experiences people with end stage renal failure have about their pre-dialysis education needs and the factors affecting their treatment decision-making.

The credibility of the conclusions drawn is supported by the data presented in the results. Secondary coding by academic supervisors has ensured the reliability of the conclusions drawn from the data. This included individual open coding of the first three interviews, comparison of the coding for agreement and discussion of category and sub-category development for fit and consistency. The contextual data provided in the study allows the reader to gauge the degree of similarity to their own context and increase the transferability of the findings. Conformability is achieved through the presentation of direct participant quotes, to illustrate how conclusions have been derived. These elements of: credibility, reliability, transferability and conformability (Guba and Lincoln 1989) are central to the trustworthiness of the research (Irvine 2007).

I was responsible for conducting and analysing all of the interviews. However, it is acknowledged that despite the use of reflexive practice, the

researcher's position as a member of the hospitals nephrology team and sole interviewer had the potential to influence responses. Despite assurance of participant confidentiality and anonymity, one cannot dismiss the potential for more positive responses. This small-scale exploratory study in conjunction with the literature review has however created a foundation for the Modelling phase of the Complex Intervention Framework (MRC 2000).

The avoidance of complex information as a coping mechanism has been identified in some individuals. For a range of reasons some individuals fail to engage with pre-dialysis education. However, education of these individuals remains important to improve their treatment understanding and ability to make informed decisions. HCPs need to be highly skilled in their psychological approach to patient education in order to develop a supportive partnership that cultivates confidence. Conversely, for those who engaged with the group education in this study, it was found to be beneficial in expanding their understanding through; information provision, their own and other participants' questions and peer support. This is in agreement with other chronic disease group programme findings by Lorig (2003) and Barlow et al (2005).

The terminologies used and psychological approach to the introduction of information, and especially group education, needs to project a non-threatening situation, so as not to alienate the less confident section of the renal population. This finding is consistent with that reported by Lorig (2003), where individuals' lack the confidence, to access and participate in the chronic disease self-management programme.

By educating the educators in the delivery and content, the model of group education could be improved. We would suggest that by developing patient education programmes, the new skills acquired by staff have the potential to promote high quality healthcare professionals, who can as the NHS Improvement Plan (DoH 2004b) suggests, work effectively in partnerships between primary care and specialist services. The opportunity exists for renal patient education to benefit from the experience of diabetes-structured education. Patient education for people with diabetes is evidence-based and delivered with the support of the National Institute for Clinical Evidence (NICE-CG66 2008) and Davies et al 2008); in the form of group (e.g. DESMOND programme (www.diabetes.org.uk [Accessed] 2008) and with 1:1 individual education delivery (e.g. Diabetes Manual, (Sturt *et al.* 2008).

It has become clear from the study data, that there are key individual decision criteria participants have, that override all other considerations when making treatment choices. Some are fear-based; others are to do with preserving autonomy. From the data, age, disease progression and patients' emotional/psychological state, especially fear, influence individuals' decision-making. This has implications for the HCPs delivery of education and the need to understand individuals' values and beliefs surrounding kidney failure and its treatment in order to deliver tailored information and increase engagement.

Participants' decision-making preferences have also been found to relate to their degree of confidence. This influenced the amount of control and responsibility they wish to have regarding their treatment decisions, and how

much they wish HCPs or carers to assume. Furthermore, it may be indicative of individuals' level of understanding about the differing treatment choices. Participants with a limited cognisance of the treatment options and/or their implications were less likely to make an active treatment decision and were more likely to opt for hospital based haemodialysis. However, the influence of their underlying psychological status cannot be underestimated. The individual's values, expectations and experience should guide informed decision-making.

The data identify Nephrology consultants and Clinical Nurse Specialists as positive and beneficial education sources, and confirm the influence and importance of therapeutic relationships between patients and clinicians. This emphasises how important it is to maximise these relationships to enhance patient benefit. Person-centred counselling skills advocated by Rogers (2003), can significantly improve these important relationships through which treatment decision-making is mediated. The application of a theoretical foundation to the educative process would guide the development and delivery.

Adaptation of information to individual need will require experienced and skilled HCPs. The role of HCPs will be a pivotal element in the development and delivery of pre-dialysis education. Clear identification of education delivery methods will be central to facilitating informed treatment decision-making.

Good written information was highlighted as important to participants in this study. This could be perceived as being contrary to Winterbottom et al's

(2008) findings of poor renal information quality. However, consideration must be given to the participants' lack of comparative information to judge written information by and the fact they don't at this stage know, what they don't know. This can result in an inability to judge the quality of information supplied (Bandura 1977). The fact remains that participants valued the written information and participants drew attention, to the importance of being able to share information with family and carers. This has implications for written information utilised in pre-dialysis education.

Written information needs to appeal to a diverse array of individuals with varying approaches to knowledge acquisition and differing levels of confidence in knowledge acquisition. Crucially, written information needs to support individuals understanding of what the options mean for them and how they fit with their lifestyle and values. Written information needs to meet the quality criteria identified by Winterbottom et al (2008).

Planned expert patient contact resulted in reports of positive impacts on participants' understanding of treatment options, treatment practicalities and particularly in allaying treatment-related fears. Expert patient contact is an effective education format within other chronic disease disciplines (Lorig et al 1999, Barlow et al 2005a). However, the unique nature of unplanned patient contact upon renal patients' treatment decision-making cannot be underestimated, particularly when the majority of unplanned peer contact reported in this study resulted in negative impacts. This has important implications for education delivery and requires careful consideration of how best to incorporate positive peer experience during the pre-dialysis journey. The

impact of negative vicarious learning has not previously been identified in the renal literature and requires further exploration in the Modelling Phase (MRC Framework 2000).

It could be surmised that organised expert patient contact with well-maintained dialysis patients needs to be incorporated into the early stages of patient education. The avoidance of participants' first impressions being based on unplanned contact is critical. The potential exists for a negative impact on pre-dialysis individuals' future treatment decision-making. This issue needs to be recognised, with service providers acknowledging the issue, exploring individuals experience and working actively to counteract the impact of negative peer contact.

Ultimately as individuals become experts in their own condition and their response to illness is based on life experience, the individual is in charge but requires backup from health professionals (Koch *et al.* 2004). It is important to be aware that information seeking has been associated with a positive adaptation to chronic illness. However, the inability to absorb information and the misinterpretation of information, as highlighted in this study, may be associated with what Iles-Smith's (2005) identifies as a lack of consideration in the quantity and timing of education provision. Tailoring of education delivery to the stage of kidney failure is already advocated (NICE 2008). However the timing of education delivery and the impact of this requires further exploration over the period of the individuals pre-dialysis journey.

Conclusion

People's illness journeys and educational needs are varied. Participants demonstrated that decision-making and treatment choice are highly individual, influenced by healthcare professionals and objective written information and peer contact. The findings suggest that a single educational intervention would fail to provide the wealth, variety and individual levels of education desired. Group education though cost effective is unlikely to be appropriate for all individuals. Individuals' illness journeys reflect fluctuating levels of wellness that influence educational need. The complexity of treatment decision-making and the responsibility this infers for people with ERF is considerable. The ramifications for life-style, health-related quality of life and ultimately mortality, based upon their decision-making is unique to the renal population.

There are key individual decision-making criteria some individuals have, that override all other considerations when making treatment choices. These need to be identified and acknowledged by HCPs. Avoidance of complex information appears to be a coping mechanism used by some individuals and merits recognition. HCPs need to be highly skilled in their psychological approach, to best facilitate the education of people with ERF and this may require the development of specialist training for educators. A theory based, multi-component pre-dialysis educational intervention, facilitated by trained educators, needs to provide patient education that is individualised and disease-stage appropriate, thus enabling informed treatment decision-making. Use of self-efficacy theory may help individuals to develop the

confidence to confront and cope with the uncertainties, which are often the basis of their treatment decisions. If patients had more confidence in their ability to self-care they may make different decisions and be more able to cope with the consequences of those decisions.

These findings bore relevance to participants' experience at the time of the study and in the context of information delivery and treatment decision-making at UHCW. However, the findings raise questions and issues. These in conjunction with the literature review findings will inform the development of the Participant Action Research Study. They have helped to build a robust Theory Phase within the MRC Framework (2008). The Pre-Dialysis Study will offer the opportunity to compare and contrast these findings in light of ongoing development and changing education delivery within the pre-dialysis education environment.

Modelling Phase

Chapter Four:

Methodology

Chapter Four: Methodology

Introduction

Pre-dialysis education provision in the UK is ad-hoc due to the lack of established guidelines or comprehensive literature on the specific educational components required and their effectiveness. There is vast discrepancy in the education available to people with renal failure, with variation between hospitals and even within the same renal department. Exploration of pre-dialysis education within the context of a single renal department can begin to establish current practice. Once established, the opportunity exists to investigate the potential and actual effect of changes to education, through the development and delivery of pre-dialysis education. The inclusion of all stakeholder groups within such a process is crucial to applicability, practicality, implementation and ultimately success or failure.

An Action Research Study aimed to develop and deliver pre-dialysis education based on a consensual process involving HCPs and service users and was informed by the MRC Framework Theory Phase findings. A detailed understanding of the decision-making process used by patients in making treatment options, needed to be achieved. This included understanding factors influencing the process, the dynamics of patients' decision-making, how they felt about their decisions and how all of this was influenced by the educational inputs they received. A Grounded Theory approach explored individuals' subjective experience of pre-dialysis education and treatment decision-making.

Continuous Literature Review Up-dating

Identification and reviewing of pertinent literature, based on the original search strategy and criteria, continued throughout the study period. Journal alerts were set up to identify the relevant literature published and the search criteria was repeated every 3 months. Literature identified post March 2009 continued to inform study progress. These subsequent studies from April 2009- December 2011 are presented in Appendix 1. The findings from the on-going review of literature inform the arguments, reflections and considerations, throughout the Discussion & Conclusion Chapter.

Consideration of the Research Paradigm

The first two phases of the MRC Framework clearly require qualitative inputs and the rationale for adopting a constructivist paradigm approach is set out. This decision has been based on two primary issues: firstly the aims of the research enquiry and secondly the researcher's philosophical stance. The research paradigm offers a "world view" (Patton 1990) and this conceptual framework helps us to see and make sense of the world. Central to consideration of the most appropriate paradigm was the aim of the studies and the knowledge required to achieve them. The relevance of the positivist paradigm is deliberated first. Consideration is given to the existing knowledge of pre-dialysis education and the research gap identified by the literature review.

Qualitative methods fit with the findings from the literature review that shows a gap in the knowledge about pre-dialysis educational interventions and their impact on treatment decision-making. Educational input and treatment choice are investigated quantitatively, and barriers to treatment choice explored qualitatively. However, there remains a research gap in terms of capturing the individual's subjective experience, of the pre-dialysis education and decision-making journey, as the studies do not seek to identify or understand social processes. The pre-dialysis education and treatment decision-making journey is a social process. Employing the positivist paradigm would not facilitate access to the potentially dynamic nature of education and treatment decision-making. It would seek to quantify, rather than explore, the education development and the individual's experience of the pre-dialysis journey. A paradigm that reduces individuals to variables, without determination or values, does not fit with the aims of the research or indeed the researcher's constructivist philosophical stance.

Consideration of the Constructivist Paradigm

The constructivist paradigm is ideally situated to develop areas of enquiry where further exploratory research is required. It aims to:

“Emphasise the dynamic, holistic and individual aspects of the human experience and attempt to capture those aspects in their entirety, within the context of those who are experiencing them” (Polit & Hungler 1997, p15).

This subjective approach to the study of social phenomena focuses on qualitative analysis, to construct concepts and theories. Corbin & Strauss (2008, p 10) explain that:

“Concepts and theories are *constructed* by researchers, out of the stories that are constructed by research participants, who are trying to explain and make sense out of their experiences and/or lives, both to the researcher and themselves”.

Corbin and Strauss argue that it is these multiple constructs, which allow analysts to construct knowledge. As themes emerge from the research, constructivist design can evolve over time to incorporate features not in the original design. It is this flexibility and the themes derived from multiple constructs, which allow researchers to construct knowledge (Corbin & Strauss 2008).

With the constructivist researcher considered to be the data-gathering tool, my position as a nurse researcher within the study site’s renal department, will facilitate my subjective submersion in the pre-dialysis, naturalistic setting. Additionally, studying part-time for a PhD, affords the opportunity to conduct the inquiry over an extended period of time. These circumstances coalesce, to facilitate the elucidation of the multiple dimensions, of the pre-dialysis education and decision-making process. The result is the production of rich, thick data. The flexibility to capitalise on emergent themes, allows direct exploration and analysis of narrative subjective data, to understand the lived human experience better.

Consideration of the Critical Theory Paradigm

Critical theorists such as Adorno, Horkheimer and Marcuse identified critical and creative thinking in the 1950s (Holloway & Wheeler 2002). The integration of human values and interests, into a framework that also encompassed ethical and critical thought, was an attempt to add to positivist and constructivist research. Critical theory, in its broader sense was, developed by Habermas (1974) who described human behaviour in terms of interests and needs (Holloway & Wheeler 2002). However, social science maintained the necessity for rigorous knowledge:

“Modern critical social theory aims to promote change and is related to the concepts of justice, power relationships between groups and social institutions” (Holloway 2008, p58)

Critical social research such as action research could, if based on this theory, result in a change in the pre-dialysis education delivered. Those involved through a more comprehensive understanding of the social conditions would initiate change. Ideally a problem-solving enquiry of this kind is collaborative and critical (Bryman 2008). The researcher aims to bring about change in a supportive and non-hierarchical environment. Central to this is symmetrical communication and becoming critical (Kemmis & Carr 1986). In reality the result is collaboration, where everyone contributes equally, though differently, to solve the research issue. Individual talent needs to be identified and used efficiently (Bryman 2008)

For real transformational change to occur, critical theory requires the collaborators to be critical and to have a self-critical attitude. In this way

change can be brought about in inequality and power dynamics (Holloway 2008). Though identified as a separate paradigm to constructivist, a number of philosophical underpinnings are shared as Holloway (2008, p58) identifies:

“Critical qualitative research is dialogic, reciprocal and based on relationships of equity”.

The pre-dialysis education and decision-making process is complex. The positivist paradigm is shown to be appropriate only when variables can be objectively identified and measured. Conversely, the constructivist paradigm seeks to understand how and why something is happening in the wider context. The critical theory paradigm aims to problem solve.

Therefore, the choice of paradigm is directed by the nature of the aims and knowledge sought of the phenomena to be examined, their context and the affinity of the researcher. The constructivist and critical theory paradigms employ qualitative methodology and are therefore amenable to guidance by the MRC Complex Intervention Framework, as a hierarchy to direct overall study development.

Modelling Phase and Study Specific Methodology

This chapter will now present, in two distinct sections, the research methodology in The Modelling Phase. In Section One, **Participant Action Research** (PAR) will explore the current pre-dialysis education circumstances at the study site and provide the framework within which to work with a renal multidisciplinary HCPs' team and expert patients to

enhance provision. Section Two presents the **Service Users Pre-Dialysis and Treatment Decision-Making Experience Study** grounded theory methodology.

Section One: Participant Action Research

Introduction

Contemporary Action Research (AR) has continued to grow as an intellectual and social movement in education, healthcare and beyond. The AR methodology in this section of the chapter will first identify the pertinent research aims. Then AR epistemology and contemporary definitions will be identified. Selection of the AR methodology to be employed will be considered and justified. The use of Participant Action Research (PAR) will be discussed and the analysis and validation issues will be explored. Methodological issues associated with the researcher as a facilitator will examine reflexivity, and insider verses outsider researcher considerations. Finally, the potential ethical issues associated with AR and the suggested combative remedies will be explored as the AR section is concluded.

Action Research Aims

People with established renal failure face a multitude of decision-making situations, in what is essentially a life-threatening disease state. The concern based on empirical experience, is that treatment decisions are made for, rather than with, many patients. This is further compounded by the lack of consistency in the approach to individualised patient education and this is borne out in the literature review chapter. Action Research potentially provides an appropriate methodology in the pre-dialysis education context to

establish how to improve pre-dialysis education by exploring the following the research question:

- What should a learning theory and health policy informed pre-dialysis education intervention comprise?

It is this research question that will guide considerations in the identification of the most appropriate methodological approach to employ.

Action Research Definition /Epistemology

The participatory nature of action research provides the opportunity for individuals to identify issues within their own communities and facilitate change. Common features at the core of all action research approaches are concerned with action to develop practices, within a social setting. This is central to pre-dialysis education that is presented by multidisciplinary HCPs to a diverse range of pre-dialysis patients. The result is an interventionist, enquiry-based approach to achieving change, which is reflective and collective in nature (Vezzosi 2006). Action research has been defined as

“A form of self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their practice, their understanding of their practices and the situations in which these practices are carried out”. (Kemmis & Carr 1986, p 46)

As a research methodology, action research is commonly referenced to Kurt Lewin in 1946 America (Greenwood & Levin 2007). Lewin developed a three

stage process of (i) deconstruction, (ii) change and (iii) locking of a permanent structure, which was further defined and challenged by Gustavsen (1992) and Eldin & Levin (1991). They argue that contemporary action research emphasises on-going dialogue and sustained change. McNiff & Whitehead (2006) contend that Lewin continues to be influential, as researchers use the original stages of the process as cyclical steps of; observe-reflect-act-evaluate-modify, to organise and report their work. One therefore acknowledges that Lewin provided the fundamental cornerstone upon which these principles could be established.

Modern Foundations

The modern foundation of human inquiry and cooperative inquiry was arguably established by the New Paradigm Research Group, in London 1977 (Greenwood 2007). Greenwood & Levin (2007) defines his vision of Action Research as:

“Human enquiry or cooperative inquiry shows how Action Research can support knowledge creation by bringing explicit, tacit and emotional knowledge together to improve organizations and the welfare of individuals” (Greenwood & Levin 2007, p 27)

Stringer (2007) concurs with this perspective and defines Action Research as fundamentally grounded in the qualitative research paradigm. More specifically, it is located within the methodological and epistemological developments associated with Critical Theoretic research. McNiff &

Whitehead (2006) highlight three components of critical theory research; (i) in order to change a given situation it must be understood; (ii) people construct social situations, hence they can be deconstructed and reconstructed by people; (iii) situations need to be defined in terms of what brought them into existence, with specific consideration of the power differentials in relationships.

It has been argued that action research goes beyond the critical theory stance, of understanding a situation in order to change it, by aiming for understanding about how it can be changed (McNiff & Whitehead 2006). The involvement of renal service providers and renal service users aimed to understand the situations from diverse perspectives, so that current practice could be challenged and new approaches developed. Focus was on 'how' pre-dialysis educational components work, rather than just 'what' was happening, leading to a better understanding of stakeholders' perceptions, interpretations and responses to investigated issues (Stringer 2007).

The way in which practice can be changed became a central element of the research process. Reason & Bradbury (2008) suggest that questioning how a situation can be improved is a common starting point for action research. In essence, a localised study has investigate localised issues. Essentially, the action researchers were part of the reality they were studying. At its most effective, action research is argued to be phenomenological, interpretive and hermeneutic; stakeholders gained clarity and understanding of an issue, and utilised this to construct effective solutions (Stringer 2007).

A living theory approach to action research identified the relationship of factors to one another, and the researcher was accountable not only for their own learning but their influence upon the learning of others (McNiff & Whitehead 2006). Stringer (2007) argues that the principles of democratic dialogue and communicative action, defined respectively by Gustavsen (2008) and Habermas (1984), are consonant with this concept. More recently whilst writing about "Truth and Justification," Habermas (2003) defines critical participatory action researchers as aspiring to consider all view points and take account of them impartially and equally.

Constituents of the basic action research steps were; a review of current practice, identification of an aspect to be investigated, imagining a way forward, trying it out, and taking stock of what happened (McNiff 2002). Based on these findings the process continues in a cyclical form by; modifying what is done in the light of what has been found, and continued working in this new way (try another option if the new way of working is not right), monitoring what was done, review and evaluate any modified action, and so on (McNiff 2002).

Adaptation of Lewin's original graphical representation of the action research cycle, reflects how the process worked as issues were addressed by a collaborative group, and is shown in Figure 4.0.4

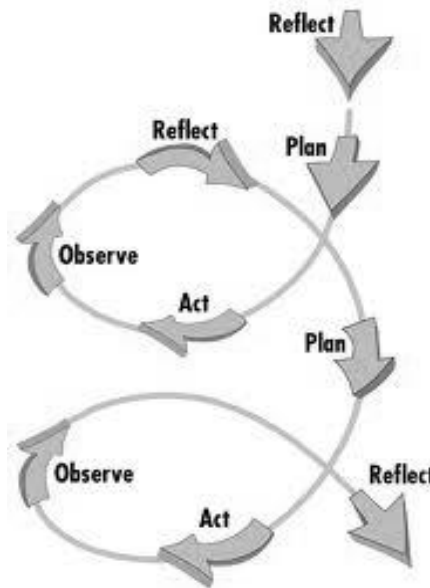


Figure 4.0.0 Action Research, Principles and Practice. (McNiff 2002)

This simplified process model has however been criticised for its representation as a series of steps, rather than a dynamic process that encourages creativity (Hopkins 1993). McTaggart (1996) asserts that the key is a commitment to core principles and ideals. This series of commitments for conducting social enquiry, have been explored and found not to be cognisant with a step-by-step approach (Townsend 2009). Mindful of this view and the oversimplification of the graphical representation, the need to be aware of the true multi-dimensional cyclical nature of action research was recognised. Additionally, the use of a cyclical process emphasises the on-going reflection and evaluation of the situation under change and avoided development of a blame culture, if change was unsuccessful. This is an important consideration when involving HCPs in research to change practice. The threat of retribution for unsuccessful change needed to be removed from the process if individuals are to engage honestly and openly with the research process. By taking the simplistic basis of a cyclical approach, with

the aspiration of participation and change, action research provided an appropriate foundation upon which to explore pre-dialysis education provision safely.

Consideration of Action Research Approaches

Definitions of action research vary greatly, dependant on the differing view point of the author and their epistemological standpoint. Greenwood & Levin (2007), introduce the notion of a process of collaborative knowledge development, achieved through a mutual learning process, involving local stakeholders. Stringer (2007) concurs and further defines the context within which it is based, as specific situations and localized solutions, to be the focus of action research. Though action research is not a traditional positivist paradigm, it still maintains the rigour of a systematic approach.

Three distinct modes of action research have been proposed: technical collaborative, mutual collaborative and enhancement collaborative (Holter & Schwartz-Barcott 1993). Concurring with these broad definitions Berg (2006), elaborates on the use of each mode. These are defined in Table 4.0.1

| Action Research Mode | Mode Goal |
|---|---|
| Technical/scientific/collaborative | To test a particular intervention based on a pre-specified theoretical framework |
| Practical/mutual Collaborative/deliberative | Seeks to improve practice-and-service delivery |
| Emancipating/enhancing/critical science | Assist practitioners in lifting their veil of clouded understandings, and help them to better understand fundamental problems by raising their collective consciousness |

Table 4.0.1 Action Research Mode & Goal (Berg 2006)

Alternatively, Reason & Bradbury (2008) use a visual depiction of the overlaps and relationships between the elements of participation, action and research: Figure 4.0.2

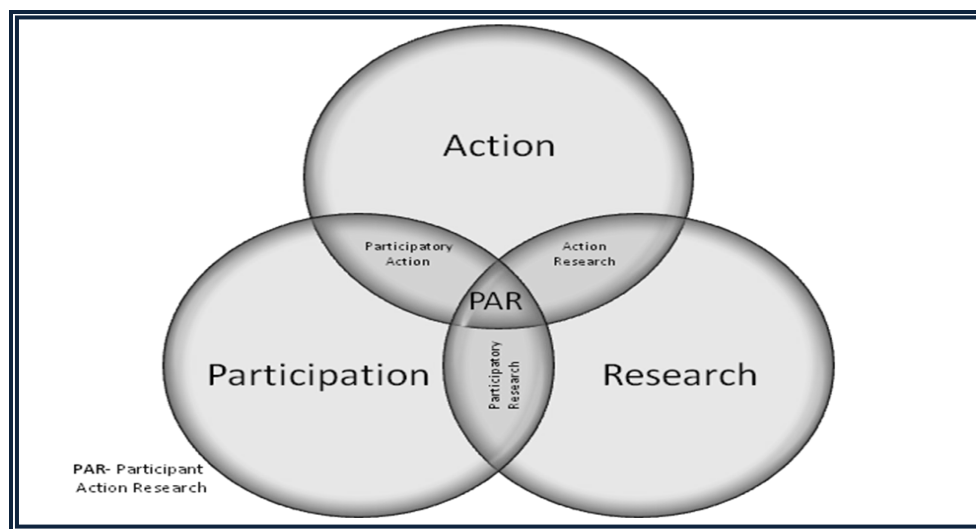


Figure 4.0.2, Relationship between participation, action and research (Reason & Bradbury 2008 p385)

The features of these overlapping, yet distinct approaches are identified by Reason & Bradbury (2008) as:

- Action Research utilises cycles of action and reflection to improve the practice of professionals.
- Participative Research involves a stakeholder coalition but is devoid of an intervention.
- Participative Action is an instrument designed and implemented by a coalition of stakeholders.
- Participant Action Research combines all three elements.

The key elements highlighted are therefore the use of systematic enquiry, decision-making involving all relevant stakeholders, and professional practice intervention (Reason & Bradbury 2008). Participant Action Research (PAR) methodology was therefore particularly suited to exploration of the pre-dialysis educational environment. The Pre-Dialysis Study aimed to design and implement, through systematic enquiry, an educational intervention. The study sought the participation of stakeholders in the decision-making process, to effect change through the use of action reflection cycles, upon a professional practice intervention.

Participatory Action Research Justification

The social research basis of action research aimed to link theory to practice and ultimately improve practice. Participatory Action Research (PAR) methodology was particularly appropriate in a hospital-based pre-dialysis setting. By involving inter-disciplinary renal healthcare professionals and services users in collaborative social research, participants had ownership of the implementation and evaluation of change. They also aided establishment

of links between theory and practice. A PAR approach to research and development, proposed that different stakeholders work together to develop and evaluate an initiative (Reason & Bradbury 2008). It has been used widely in health care and community development settings.

Cohen & Manion (2007) define action research as the investigation of a problem, which has been identified by practitioners, and is aimed at greater understanding and practice improvement, over a period of time. Stringer (2007) concurs and defines the context within which AR is based, as specific situations and localised solutions being the focus of action research.

Hart & Bond (1998) argue that there is interplay between AR approaches as research progresses. The notion of interplay between modes is important. Even when employing a participatory approach to achieve practical service development, the potential for and benefits of, emancipator effects should be recognised. The research approach for this study, though participatory, was potentially positioned to combine elements of an experimental and organisational approach, with a view to facilitating empowerment of participants (Hart & Bond 1998).

Hart & Bond (1998) suggest, the contribution from collaborators is crucial in change initiatives. Smith & Cantley (1985) argue that PAR provides a plurality of operating tactics and perspectives at work. Broader consideration of the requirements for successful PAR were explored by Swantz (2001, cited Reason & Bradbury 2008) Swantz argues that support for an AR methodology approach needs backing at the highest level.

“In a hierarchical, bureaucratic system support from the higher authorities is a necessity if participation is to become a general approach” (Swantz 2001, p 387).

Conflict may arise when PAR is facilitated by a researcher committed to the emancipation of oppressed communities, but who is working within the confines of a hierarchical organisation that does not support or is not amenable to participatory research.

Traditionally within the NHS, value is placed on evidence-based practice, acquired through academic knowledge and understanding. This in itself is a hierarchical notion, which defines the knowledge provider as the expert and therefore confers authority. The notion of valuing practical and experiential knowledge of those living with an issue was a challenge to the established model of practice development. However, the MRC Framework (MRC 2000) addressed these concerns and places value on qualitative methodologies and guided study development within the framework, to build towards RCT's. The MRC Framework therefore provided robust and authoritative support, to justify developing complex intervention proposals in healthcare.

PAR can be questioned, where patient satisfaction surveys have or could be utilised. The potential for tokenistic participant involvement to achieve target tick-boxes was identified in the form of satisfaction questionnaires (Northway 2000a). Satisfaction questionnaires it is argued are generally based on the HCPs' opinions of what is important and perpetuates the paternalistic authoritarian practices entrenched in healthcare provision. PAR has

challenged such dogma with a methodological approach that requires active participation throughout a research project (Northway 2000a).

The notion of conducting a project jointly requires caution. It may wrongly be assumed that all participants want to engage in the analysis and dissemination. Furthermore, in a multidisciplinary collaboration, the fluctuating demands of individuals' workload or health status, make commitment of time an issue. Committing to set meetings was one thing, taking on extra workload was another. Individual expertise and commitment, so valuable to a collaboration, may have been lost if the project was seen as too onerous. Hence, there was a fine balance between the demands and payoff for individuals. The opportunity to take ownership and be involved in all phases was offered, encouraged and supported but not expected or imposed.

Participatory Action Research Methodological Issues

Validity

An action research group provided the opportunity to focus on a phenomenon of interest. Discussion and understanding of the subject, from multiple perspectives then occur whilst collaborative working relationships were established. It is these complexities of social interactions between individuals and professional groups, which have been explored to establish the validity of action research (Anderson & Herr 1999). Analysis of PAR needed to encompass an understanding of how an effective pre-dialysis

educational toolkit is created. Equally important however, was the process by which this is achieved and policy was formulated and implemented. Adaptation by Newton & Burgess's (2008), of Anderson & Herr's (1999) action research validity framework, identified specific primary and secondary validation issues, which were specific to the research mode. These are defined in Table 4.0.3

| Action Research Mode | Primary Validity | Secondary Validity | |
|-------------------------------------|---------------------|---------------------|-------------------|
| Knowledge generating | Outcome validity | Democratic validity | Dialogic Validity |
| | Process Validity | Catalytic validity | |
| Practical (improvement of practice) | Catalytic validity | Process validity | |
| | Outcome validity | Democratic validity | |
| Emancipatory | Democratic validity | Process validity | |
| | Catalytic validity | Outcome validity | |

Newton & Burgess's (2008) adapted from of Anderson & Herr's (1999)

Table 4.0.3 Action research modes & corresponding validities

The validity framework offers a clear and transparent approach to detailing the PAR or practical mode. Primary validities aimed to establish to what extent the primary goals of the PAR have been achieved. Catalytic validity focused on the process whereby participants deepen their understanding and are motivated to social action. Outcome validity identified the extent to which the research outcomes were successful. Secondary validity focused on the research mode domain. Process validity was concerned with the evidence needed to sustain assertions. Finally, democratic validity recognized the extent of collaboration amongst stakeholders. Though action research is not

a traditional positivist paradigm, use of such a framework aimed to maintain and make explicit the rigour of a systematic approach.

On-Going Cyclical Analysis

Participant action co-researchers did not represent a homogenous group and it was this diversity, which was key to reflecting the disparate interests of local stakeholders (Boser 2006). Action research meetings provided a forum where experiences were described, qualified, contextualised, interpreted and conclusions drawn about their meaning, implications and the actions generated. Thus, a decision trail was created, to enable key points in the cyclical process to be identified, and if required, revisited. In this way the analysis and interpretation derived from the meeting was taken back into the educational intervention. Implementation over an identified period and further experiences were brought back to the action research meeting. This process was one of collectively and continuously acting on reflection and then reflecting on the action for the duration of the study. The cyclical nature of action research allowed the knowledge and skills that pre-dialysis educators have or need, to emerge and indicated where there are gaps between theory and practice. Some processes were unsuccessful, while others were implemented effectively.

Reflexivity and Objectivity/subjectivity

An additional challenge for PAR study validity was the influence the researcher as an individual brought to bear upon how the research was conducted. As an experienced renal nurse with an interest and active role in dialysis patient education, I was aware that I had preconceived notions about education and the role it can play in care delivery. It is vital that any influence this may have brought to bear upon the research was recognised and acknowledged. The researcher employed reflexivity, an overarching process of critical self-awareness in qualitative methodologies. As a consideration for all qualitative research paradigms, reflexivity required careful deliberation in relation not only to the PAR methodology described but indeed the interview and grounded theory approaches employed within this study.

Reflexivity can be defined as the researcher's awareness of their influence, upon the research process, gained through critical self-awareness. This occurred on multiple levels and reflexive complexity was increased in this mixed methods study. The on-going process of critical self-awareness aimed to make explicit the influence of the researcher on the research, and conversely the influence of the research on the researcher.

At one time emphasis was on the need for researcher objectivity, and this was influenced by traditional positivist stance, whereas contemporary qualitative research approaches acknowledge that such neutrality is not feasible. The shift in belief from researcher objectivity, to acknowledgement of subjectivity and the need for transparency of reality, is advocated by

Marcus (1994). It was the use of reflexivity that recognised and made explicit reciprocal relationships in the research (Lamb & Huttinger 1989).

Dowling (2006) highlights how epistemological reflexivity requires the researcher to question the ways in which the research questions could have been defined and investigated differently. Epistemological reflexivity, it could be argued, is central to grounded theory where experiences from previous interviews are brought to, and influence the on-going, research data collection. As the research data influences the researcher, in turn the researcher then influences the research. Throughout the research process, the use of a reflexive diary facilitated exploration of one's subjective attitudes and beliefs. It can be argued that this was further enhanced by a clinical supervisory relationship, able to explore the tension between being an object and a subject (Dowling 2006). Within the PAR arena similar tensions were achieved through the interplay with critical friends established to challenge the researcher's self-deceptions (Northway 2000b).

The feminist experiential stance was particularly appropriate with its reflexive approach to conducting unstructured interviews and in collaborative PAR. The necessity for engagement rather than detachment (Sandelowski 1986), expected reciprocal knowledge sharing, by the researcher and the researched, to enable creation of a research partnership endeavour (Dowling 2006). Engaging openly and honestly with participants' gave them greater understanding of the researcher as a person and this began to build trust in the motives and the research aims.

As an experienced renal nurse, the researcher possessed knowledge, that the interviewees want to explore and the balance between researcher and renal nurse in interviews needed to be achieved. It would have been disingenuous to deny my renal experience. However, it was possible to negotiate at the start of interviews that should participants have any renal specific questions these would be addressed following interview completion.

It has been argued that if researchers are not willing to be open, then they should not expect participants to be open (Furman 2004). A critical methodological approach that embraces the reflexive needs, of collaborative and non-hierarchical relationships, is advocated (Fontana 2004). Such an approach corresponded well to the interviewer-interviewee and PAR relationships within this study. Hence, the construction and validation of data was promoted and came about through the active role that participants played (Fontana 2004).

As a central concept in qualitative research, reflexivity adds credibility (Dowling 2006). By making the research process transparent and clearly identifying the reflexive procedure explicitly, the researcher aimed to add rigour to the qualitative research.

Insider/Outsider Researcher

The issues associated with 'insider' and 'outsider' research were complex. The relationship of the researcher to research subjects and collaborators had the potential to influence research findings and their validity. Issues were

therefore fully considered and practical steps taken, prior to commencement of the study, to limit if not completely negate, these potential effects. In this study the researcher was an insider which raised epistemological considerations relating to the focus of the research and its understanding. The ability of the researcher to engage critically, when they bring their own framing assumptions is questioned by BERA (British Educational Research Association, online 2009), asking:

How does the insider make the familiar strange?

(Stenhouse cited BERA 2009).

It was therefore important to consider what effect the insider status would have on the research process. A critique of the 'insider' and 'outsider' action research model was explored by Titchen & Binnie (1993). They offer an ethical and philosophical discussion on the advantages and simultaneous disadvantages of being an 'insider'. Both models, they argue, present tensions and issues.

In terms of achieving a desired change, the insider model was found to be more effective. Being an 'insider' researcher brings the benefits associated with the authority vested in the researcher; this was found to be influential in Action Research success (Titchen & Binnie 1993). However, when the study of a phenomenon of interest is associated with the researchers attainment of a graduate award this was found to have a negative influential effect (Titchin & Binnie 1993). This was associated more so with the 'outsider' research, where conflict arises as the researcher and participants study priorities differ.

To counter this issue, potential participant input into the original study proposal prior to ethics submission would be judicious.

The focus of the PAR was on practice and the potential to improve pre-dialysis education and its delivery and was the philosophical foundation of the whole study. Having extensive experience of dialysis patients and the wider renal environment at the study site identified my position as an insider researcher. However, having not worked directly in the pre-dialysis care environment resulted in the researcher not being viewed as experienced in this particular area, within the renal environment. Additionally, this also meant that the researcher, as main interviewer, was not known to the participants. Some of the potential tensions associated with insider research were reduced, as a degree of naivety was balanced against a comprehensive understanding of the wider service demands. Current practice could be explored for understanding and clarity, rather than as a challenge.

The potential to be perceived as academically elite within nursing circles was tempered by my lack of knowledge in relation to the phenomenon of interest and by having established working relationships with the multidisciplinary team. Involvement of the multidisciplinary team at the proposal development stage further reduced tensions and cultivated engagement.

However, having espoused the benefits of pre-proposal input, conflict arises between PAR methodology and the requisite demands of the Universities Up-grade process and Ethical Committee approval process. In PAR methodology the study focus develops from the collaborative group. Yet, when PAR forms the foundation of a PhD Up-grade process and Ethical

Committee approval needs to be sought, prior to collaboration formation, a degree of pre-determination in study direction has to exist to satisfy these regulatory bodies. The skill lay in the identification of a specific area of interest, in this study pre-dialysis education, but with a clear identification of the collaboration-led nature of decision-making, congruent with PAR ethos. To satisfy Ethics Committee requirements, potential options identified were based on the literature review, patient needs assessment and influenced by the researcher's pre-conceived notions. The suggestions for study focus were based around the introduction of pre-existing pre-dialysis education components, not currently in use at the study site.

Resistance associated with change had the potential to raises tensions in PAR and needs to be addressed (Titchen & Binnie 1993). The pre-dialysis study clearly identified participants as co-researchers and aimed to bring equity to collaborative practice. The researcher's role was to facilitate the action research, as guided by collaborative group decisions. Ownership of change focused on collaboration members from the outset with control over the implementation, cyclical evaluation and adaptation of change residing in collaborative decision-making. The aim was to diminish resistance so that integration into practice becomes established. With ownership of the PAR process, the changes affected were likely to be maintained beyond study conclusion. Such a unified approach to changing practice is argued to result from individual HCPs' reflective professional practice (Elliott 1991), a fundamental principle of action research.

Rooney (2005) identifies the insider researcher's potential to negatively impact on participants' behaviour through; misinterpretation of data due to tacit knowledge; the researcher's politics, loyalties and agendas; subconscious distortion of data due to the researcher's moral, political or cultural standpoints; and assumptions based on insider knowledge. The establishment of participants' co-researcher roles and the researcher as facilitator worked to combat these tensions. It has been argued by anti-positivists that these issues are equally as applicable to the 'outsider' and indeed all researchers (Rooney 2005) and co-researchers. However, 'insider' researchers, to their advantage, have a potential wealth of specialist knowledge and understand jargon; participants may have felt freer to talk to a known researcher; and the added richness and authenticity of information acquired, it could be argued, increased the depth of understanding.

It was not anticipated that organisational change would be required beyond the level of the participants involved in the PAR. Therefore, the researcher's role as facilitator was affirmed and the participants were the agents of change. However, it was acknowledged that establishing the roles participants took to facilitate change was a slow process. Nursing AR studies of less than a year's duration have been found less likely to succeed (Titchen & Binnie 1999). In response to this issue, the PAR study was of 18 months duration, which aimed to provide the requisite time frame to address role issues and resistance to change. The diversity of the proposed HCPs' input into pre-dialysis education delivery, was to an extent, pre-defined by their existing specialist expertise. Thus role definition was limited to participants' PAR function.

These potentially positive factors associated with insider research, counter-balanced, but did not negate, the negatives highlighted. Hence, it was imperative that vigilance of these issues was maintained. One could argue that a degree of subjectivity is impossible to circumvent in research. However, the awareness of tensions and actively working to overcome them, strove for objectivity. Honesty and transparency in the research process arguably allows readers perspectives to be constructed, and as Cohen & Manion (2007) identify, the validity of these perspectives is equal to our own.

Ethical Issues

Action research participants in the healthcare environment provide a unique insight into the social conditions within which they exist, providing invaluable information for healthcare organisations and planners. However, Oliver (2003) questions the moral acceptability and the ethical dilemma raised, in seeking help with a research programme, from those living in adverse conditions. One could argue that without such insight, as defined by those affected, patient's needs cannot be catered for and understood.

The nature of the research project itself can be perceived with varying levels of significance and value to individuals. This had the potential to affect willingness to participate. Cognisance of power differentials or perceived differentials and their potential influence was recognised. PAR is concerned with the realities of others and the power to frame their reality (Chambers 2008), by hearing their voices and democratising research. The participatory

approach was adopted with the intention of supporting HCP's and renal service users, and to develop their own awareness.

The concept of power being a multi-dimensional dynamic network of shifting relationships (Foucault 1980), was fostered within the action research collaboration, whereby, each member had the potential to influence proceedings. The challenge lay in achieving a balance in the way influence was exercised (McNiff & Whitehead 2006). With PAR forming the underlying collaborative philosophy for this research study, it was recognised that numerous challenges to achieving this existed. Greenwood & Levin (2007) elucidates these challenges as; the joint influence of the study phenomenon, environmental circumstances, the aims and abilities of the participant collaborators, and, most importantly, the professional researcher's proficiency.

Power cannot be assigned or imparted within a collaborative group. Collaboration was the ideal to aspire to and work towards. It is not, as Hart & Bond (1995) indicate, something capable of being imposed. Rather the philosophy of PAR identified power in the relationships that define collaboration and facilitated its practical and theoretical development (McNiff & Whitehead 2006). The notion that power is not a thing, but exists within relationships, was defined by Foucault (1980). Accordingly, power is a dynamic entity intrinsically linked to knowledge (Foucault 1980). Hence it could be argued that power transferred and fluctuated as the knowledge base within the collaboration shifted. Cognisance and acknowledgement of

potential power differentials within PAR took the first step toward combating it.

When all parties bring knowledge, be it academic or experiential, to PAR and all are perceived as knowledgeable in their own right, then power sharing occurs. Aiding this was the use of reflexive and reflective practice by the researcher to explore the on-going research process and make transparent and explicit, attempts to identify and resolve issues, of actual or potential power differentials. Regardless of the research methodology employed, the aim was to protect the welfare rights and dignity of participants. In situations where power differentials exist, latent coercion may be present. As the PAR facilitator it was important to remain mindful that coercion at any point in the research process had the potential to compromise the welfare ideal. Coercion is defined, as “the use of force or threats to make somebody do something against his or her will” (Encarta Dictionary, online 30.06.2009). This definition makes coercion sound a blatant and obvious activity, when in reality it may be far more subtle and insidious. Continual cognizance of power and privilege in working relationships was crucial in collaborative action research, as was the examination, and if required challenging of existing relationships. However, there is a fine line between the protection and empowerment of research participants (Bryden-Miller & Greenwood 2006).

Participation in this study's collaboration were voluntary and establishment of the group involved negotiation of roles, expression of expectations, shared decision-making and dissemination of results. Learning from multiple

perspectives gave practical and theoretical power to PAR. However, as Whitmore & McKee (2001) found, in a large PAR collaboration it was only after smaller sub-groups were formed and power relationships mediated, that the voices of disenfranchised groups of students involved in the study were heard.

Cognisance of group size and its potential effect upon individual agency required acknowledgement prior to and vigilance during, the PAR process. The aim was to guard against deprivation of influence. However, it could be argued that the very nature of collaborative action research aimed to co-generate knowledge, the contention being that this is achieved through democratic collaboration (Bryden-Miller & Greenwood 2006). The issue of anonymity verses acknowledgement in PAR, was a participants decision, and collaborators were acknowledged as co-authors. This decision is made easier for participants, it has been argued, when research results have a direct benefit to the community involved (Hammersly 2000). It was through this commitment to the democratization of human situations, that the cornerstone of action research was defended.

HCP's in the collaboration were senior members of staff with extensive renal experience. However, there was the potential for those staff directly responsible for pre-dialysis care to be perceived as, or presumed to be, more authoritative and powerful in the collaborative process. Clear establishment, from the outset, of the value of individuals' diverse perspectives, experience and expertise and the benefits this brought to the collaboration was crucial and was revisiting during the process. This was especially true in ensuring

service user voices were heard. By ensuring the invited service users were not directly cared for by any of the HCP's involved in the collaboration, reduced the likelihood of service users reticence to be critical of those influential in their care delivery. It was the role of the PAR facilitator to ensure that every voice is heard with equity.

Despite arguments in favour of democratization of power within the PAR, support for the process by those in strategic positions of power and influence were crucial. The Early Mothering Project, to improve midwifery practice and facilitate women's informed choice, is one such example (Barrett 2001). Ultimately, the PAR group became established as an accepted part of the hospital's practice. Barrett (2001) cites the involvement and collaboration of the Director of Nursing as a key principle underpinning the success of the initiative. Support from senior colleagues cannot be under-estimated. Equally, upholding the underlying philosophy of mutuality and equality within collaboration is what maintained interest and brought validity to the process (Whitmore & McKee 2001).

Potential participants in action research required an honest risk/benefit analysis if they were to make an informed decision about their involvement. In the continuing reflective cyclical nature of PAR, awareness and openness about the balance between paternalism and protection; concern and control, was reflected upon, not only by the researcher, but also the collaborative group. Use of a reflective journal by the researcher ensured ethical issues were recorded and acted upon where necessary. This was a routine strategy integrated into the research cycle. By sharing, personal reflections with the

collaborative group, the notion and impact of reflective activity began to be established as part of normal practice.

Cultural Issues

Inevitably cultural differences inherent in a given population, though inescapable, featured in PAR reflections and raised ethical issues. Though some participants were pre-dialysis patients at the study site, they were far from a homogenous group. In the same sense the HCP participants were a heterogeneous group. They possessed certain factors in common i.e. Study site renal services, HCP status or a degree of renal failure. However in many ways they differed not only from one another, but also from the researcher (Oliver 2003).

The varied cultural background of participants affected their responses to the research proposed and data collected. To combat this, the PAR design allowed respondents to be fully cognisant of what was being asked, and permitted comprehensive articulation of attitudes and values pertaining to the questions asked (Oliver 2003). Validity in interpreting respondents' answers had the potential to be further compromised by cultural differences between the researcher and the participant. Oliver (2003), highlights the importance of subgroups, potentially in this study service users and the effect on participants' perspectives of a situation, and the researcher's appreciation of this.

The collaborative nature of action research and its iterative, cyclical nature provided a culturally diverse forum to review and discuss the researcher's interpretations of the data. Action co-researchers and participants represented a diverse group, reflecting the disparate interests of local stakeholders (Boser 2006). The democratic review and consideration of these individuals' views by the action research collaboration, sought to build validity into study findings. Ultimately, asking participants to review their responses as interpreted by the researcher added validity to the findings. Such a review process goes some way to identify cultural differences.

Using the review process was an extension of reflexive practice and ensured the researchers unbiased and improved accuracy and representation of the culturally diverse participants engaged. The very essence of the action research study was to identify educational components that are useful to pre-dialysis patients. The wealth of cultural diversity present in this population benefits the generalisability and thus application of any findings in other contexts.

Terminology Issues

The emphasis in qualitative research is based on the individual's perspective and the contribution this makes to the collective nature of society. Hence, the term 'participant' as opposed to 'subject' or 'respondent' is according to (Oliver 2003), more harmonious with the philosophy of qualitative action research. Participants in the PAR were identified as co-researchers. Oliver (2003), goes on to identify the lack of power and status differential when

'interviewer' and 'interviewee' are utilised as a pairing and as a means of conveying the data collection methodology. It is in valuing and respecting the participants by the qualitative researcher that can promote power sharing.

The term 'nurse-researcher' had the potential to raise issues of conflict of interests. Are you a nurse or a researcher? This is an issue that needed to be defined and established prior to study commencement. As an insider researcher it was vital that this distinction was created. When interviewing participants the researcher role was to the fore and to minimise the influence of their clinical experience, as this had the potential to introduce bias into the research relationship. Terminology was an important consideration, requiring sensitivity to potential connotations, and was influential in highlighting and combating coercion.

Professional Guidelines

As a nurse researcher and PhD student, the researcher's practice was governed in a number of ways, and these served to protect the public and professional alike. The professional code of conduct, pertaining to the nurse researcher as a member of the Nursing and Midwifery Council, dictated that as nurses the first concern is the care and treatment of people as individuals with respect for their dignity. The code further demands collaborative relationships to protect and promote health and wellbeing; provision of high standard practice and an open and honest approach that defends both professional and personal integrity (NMC 2008). These values were further compounded with the application of the Research Governance Framework

for Health and Social Care (Department of Health 2005d). The framework sets out the principles, requirements and standards to be applied to research studies; defines the mechanisms of application; and describes both academic and clinical monitoring, and assessment arrangements. Its aim was to improve research and safeguard the public. Clear identification of the specific responsibilities of key stakeholders involved in the research process, aimed to achieve this.

Conclusion

Located within the participatory action research approach, the use of reflective practice aimed to enhance both individual and professional control of the work environment. Research was the dominant factor but the approach was dynamic and adaptable within the cyclical nature of action research and participants' roles had the potential to become merged as individuals' research interests were encouraged (Hart & Bond 1995).

The social research basis of action research, it could be argued, aimed to link theory to practice and ultimately improve practice. PAR was particularly appropriate to the hospital-based pre-dialysis setting. By involving interdisciplinary members of the study site, nephrology department, and service users in this collaborative social research they not only had ownership of the implementation of change, but also helped to establish the links between theory and practice. The specific Participant Action Research methods are described in Chapter Four 'Methods'.

Section Two: Service Users Pre-Dialysis and Treatment Decision-Making Experience: Methodology

Introduction

The in-depth exploration of patients' pre-dialysis educational experience and understanding of their treatment decision-making processes was fundamental to this study. The literature review showed clear gaps in the current understanding. There was a lack of literature or guidelines relating to the usefulness of specific renal educational components. Current practice was ad-hoc and at best based on the literature pertaining to other fields of nursing, such as diabetes education and long-term condition self-management.

This section explores the patients' education needs using a grounded theory approach as a framework within which patients' education needs could be understood and findings could be interpreted. The methodology is defined and consideration is given to different approaches and data analysis.

Definition

The champions of the interpretivist approach to developing theory from qualitative data are Glaser & Strauss (1967), who formalised grounded theory. Development of theory from data is a central tenant of grounded theory and is achieved through an iterative process whereby data collection and analysis proceeds in a cyclical fashion or research spiral (Lewin 1946), where analysis is not separate from data gathering, but is in fact central to

the refinement of questions. Constant comparative analysis between new and analysed data occurs both within and between interviews (Bryman 2008), making possible the adaptation and reformulation of both research and interview questions based on data emerging from interviews. Ultimately, the aim was to develop theory by defining themes and exploring the ways in which they interact in people's experiences.

Consideration of Methodological Approaches

Grounded theory provided the best fit for the research topic under investigation, where adaptation and social problems e.g. decision-making about renal treatment, were an issue (Benoliel 1996). Through knowledge development, facilitated by the grounded theory process the aim was to move from description, to the understanding of what was happening. Ultimately, substantive theory or rich, thick descriptions are produced to identify the specific educational interventions that are beneficial to pre-dialysis individuals and the impact these have on their treatment decision-making. However, grounded theory is not a single methodological approach; indeed since its inception by Glaser & Strauss (1967) the original authors', divergent methodologies have added complexity to the methodological conduct of grounded theory.

Grounded theory in its classic Glaserian (Glaser & Strauss 1967) form is an interpretivist epistemological approach to research. As such it stems from a post-positivist paradigm. Alternatively, Straussian (Corbin & Strauss 2008)

constructivist ontology holds that social interaction produces social phenomena. Therefore, individuals play an active role in the construction of social reality and provide a post-modernist and post-structuralist paradigm. It was the understanding of how individuals engage with the pre-dialysis educational environment reality that identified the impact it had upon their treatment decision-making. Both approaches to grounded theory encompass the common epistemological principle that truth and meaning are indeed not independent of, but rather created within, the human mind (Bryman 2008). Human consciousness, on an individual and personal level, engages with the realities of our environment to create meaning and truth (Crotty 1998). The conceptual orientation of grounded theory is identified as symbolic interactionism (Nusbaum & Chenitz 1990).

The Glaserian approach is considered to be more positivistic than that of the Straussian approach (McCann & Clark 2003). It was the empathetic understanding of human behaviour as opposed to the explanation of it, or forces acting upon it, that have guided this study. Inductive examination of data, which has been collected in a natural pre-dialysis context with concurrent collection and analysis, aimed to generate substantive theory of educational intervention experience and the impact upon treatment decision-making, through an iterative process. Substantive theory could then be argued to be grounded, due to the inquiry-taking place in the natural context (Corbin & Strauss 1994). Such empirical insights from individuals experiencing the pre-dialysis educational environment increased understanding of the pre-dialysis journey. Alongside this, the literature

formed the foundations that contribute to future substantive theory production and to guide further qualitative investigations (Priest et al 2002).

Justification of Grounded Theory Approach

The Straussian approach has been adopted in this study as it aims to produce an understanding of the pre-dialysis situation, which can guide practice. Corbin & Strauss's evolution of grounded theory associated with a greater flexibility of application is more attuned to contemporary thinking (Cooney 2010). The emphasis within the Straussian focus is broader than Glaserian and can therefore encompass the education and treatment decision-making cultural scene at a macro level, in addition to the micro level personal constructs of pre-dialysis participants. The use of the literature review, completed in the theory phase, is advocated by Strauss to enhance theoretical sensitivity, inform the research problem in conjunction with emergences during the study, and acknowledges personal experience (McCann & Clark 2005).

The highly structured analysis process, defined by the Straussian approach incorporates axial coding, category and sub-category linking, and will aid the identification of causal conditions within the pre-dialysis context (Stern 1994). Though this may limit the more experienced researcher, for a novice researcher coming to grips with the complexities of grounded theory, it provided clear rules and procedures, to aid analysis.

Researcher's philosophical stance

It was important to identify my worldview in terms of knowledge and acquiring knowledge through enquiry. These fundamental beliefs based on personal and professional life experience influenced my approach to and analysis of the study design in terms of method, methodology and theoretical perspective. I have observed, whilst caring for renal service users over many years, the varying extent of their ability to adjust and cope with their long-term condition. I perceive the renal environment to have multiple realities for individuals within the perspective of their social world. There is, as Crotty (2003) emphasises, no single truth. Service users construct their own social world within the renal environment and the constructivist approach facilitated the qualitative exploration of the pre-dialysis journey. Within this process the researcher was not neutral, particularly having selected to explore pre-dialysis education influences, due to extensive renal experience. However, if I were to gain insight into others experiences, I believe, I need to be open and giving of myself. It is my contention that a feminist perspective (Clark 2006), encouraged greater equity in the interviewer/interviewee relationship and aided the constructivist approach.

Methodological Issues

Unstructured Interview

An unstructured interview approach was selected as it affords the appropriate data collection means for a grounded theory methodology. A topic list is used

to elicit views and opinions from the interviewee, without the interviewer influencing the range and depth of response (Rose 1994, Fielding 1994). A criticism of unstructured interviews is the limit to sample size due to their time consuming nature and the resultant reduced generalisability of findings. Conversely, the payoff has been a greater depth of understanding and nuance that would be lost with a more structured approach (Fielding 1994). Beyond the increased ability to clarify and explore interviewee comments, the interviewer's use of prior knowledge, during the interview process was recognised (Duffy et al 2000).

Theoretical Sampling

Interviews sought to explore participants' subjective opinions of the pre-dialysis experience; therefore the method of sampling was pivotal. Theoretical sampling aimed to facilitate data collection based on the themes and concepts emerging from interviews. Glaser & Strauss (1976) assert the need to explore participants' experience, guided by emergent themes. The purpose of theoretical sampling was, as Corbin & Strauss (2008) suggest:

“To collect data from places, people, and events that will maximise opportunities to develop concepts in terms of their properties and dimensions, uncover variation, and identify relationships between concepts”. (p143)

Clear inclusion and exclusion criteria based on biochemistry results and referral to the CNS for pre-dialysis education identified those individuals for whom the study bore relevance.

Initial sampling for this study was based on the clinical need to educate pre-dialysis patients, in order for them to make informed treatment decisions. The discovery of data categories, and their refinement, aimed to uncover emergent hypotheses and integrate these into subsequent data collection. This multidirectional method of constant comparison and analysis, aimed to discover the inter-relationships between data categories and their properties.

The concept driven nature of theoretical sampling enabled in-depth exploration of concepts pertinent to the study population. The cumulative nature of theoretical sampling aimed to develop category properties and dimensions. It was these well-developed themes and concepts that facilitated theory development.

Data collection

The PhD study defined the scale of what is possible and necessitated the delineation of the sociological phenomenon for investigation. Corbin (Corbin & Strauss 2008) concur on the realities of justifying and rationalising sampling to gain ethical approval.

Data collection decisions in grounded theory are not based on a preconceived framework of concepts and hypotheses, but rather on the general problem area e.g. pre-dialysis education and treatment decision-making and its sociological perspective (Glaser 1978). It is acknowledged that many researchers will enter the field with research strategies, questions about the problem area in mind and a general perspective of beginning

concepts (Glaser 1978). Corbin & Strauss (2008) advocate a preliminary review of the literature to enhance sensitivity. This approach was especially apposite as the research was based on the findings of preliminary fieldwork. Crucially, the researcher's ability to begin coding, believe in their data, and subsequently sample based on the emergent themes, remained central to appropriate data collection.

Participant Transcript Review

Interviews with participants were recorded digitally and transcribed verbatim. The personal transcription of digital audio recordings helped to sensitise the researcher to the interview content (Corbin & Strauss 2008). Immersion in the participants' data ultimately benefitted the subsequent coding and analysis and helped to avoid transcription errors, as the researcher was conversant with the associated clinical terminology and jargon (Duffy et al 2000).

Reviewing of transcripts is advocated as sound research practice, which institutes a philosophy of participation, based on openness and collaboration (McNiff & Whitehead 2006, Oliver 2003). Participants needed to feel confident that the researcher was representing them fairly, and that they were maintaining control over their input into the research. The process, it is argued, provides verification of accuracy but also the potential to produce further data (Sandelowski 1993, Whiting 2008). Consistency of approach became the imperative and added to overall methodological rigour.

Nonetheless, by promoting additional validation participants have been reported to be shocked reading verbatim transcripts, when oral language can appear incoherent or confused (Dearnley 2005, Kvale 1996). In a study of healthcare professionals' interactions, participants reviewing their transcripts identified their inadequate grammatical expression, which resulted in the experience of a disempowering state (Manias & Street 2001). Hence, reviewing of transcripts by participants was not without issue.

Potential effects should cause disquiet to researchers and provoke measured consideration and response. Achieving a balance between the demands for validity over the needs of the individual was crucial. An alternative, advocated by Kvale (1996), is returning a summary of the interview's main points and general mode of expression, for verification. Verification of transcription is argued to be important and has the potential to bring greater credibility to research (Dearnley 2005).

Hence, a summary of the transcripts' main points was offered to participants. This was completed prior to analysis, to ensure any disputed text, did not influence the analysis of the interview data. Furthermore, a summary of the previous interview was verbally presented to participants prior to follow-up interview commencement. This had a twofold effect of identifying previous emergent themes and checking the accuracy of transcription analysis. Member checking ensured the development of themes was based on an accurate reflection of participant data. Establishment of these conditions was prior to consent and created a solid foundation upon which participants could base their decision-making.

Researcher Influence

To achieve the in-depth exploration of patients' needs and treatment decision-making, participants needed to maintain control within the research situation. It was the responsibility of the researcher to ensure that participants, to the greatest degree, felt confident to give unguarded responses; thus creating an environment conducive for interviews. Showing participants how to pause or stop the audio recording, gives greater control in the interview situation (Oliver 2003). Furthermore, offering a transcript summary review creates a shift in the power dynamics at play, in the interview situation. The sharing of information by the researcher aims to invest personal identity in the relationship and endeavoured to empower participants by facilitating a more equitable power base. The empowering and therapeutic potential of qualitative research has been fostered in feminist research approaches (Clarke 2006). This aspires to produce a non-hierarchical research relationship (Oakley 1981, Devault 1990). However, critics of this theory would argue that by simply collecting data about another individual, the very nature of the relationship becomes hierarchical (Bowler 1997). As a member of the renal nursing team, the potential influence of the researcher upon interviews was a reality. Cognisance of participants wanting to please the researcher, possibly perceived to part of the renal care team is important. Reassurance of complete anonymity and transcript review were emphasised. Dingwall (1997) argues, that the social constructs resulting from interview data are tempered by the acceptability interaction cues researchers give off, in response to individuals' accounts.

Qualitative interactionist research argues neutrality is not possible and that the research and researcher cannot be separated (Hand 2003, Lee 2009 & Northway 2000a). This corresponds to the qualitative research approach of engagement rather than detachment (Sandelowski 1986). The achievement lies in the balance between engagement and cognisance of influence. The researcher needs to focus on reflective and reflexive practice, access to expert advice and as a novice interviewer to acknowledge limitations and biases (Dingwall 1997, Loera 2006, Whiting 2008). Biases based on the values, assumptions, prejudice and influences of the researcher needs to be acknowledged within the research process (Hand 2003). Immediate transcribing of interviews emphasises to the researcher the competency of their interviewing skills. Furthermore, secondary reviewing by academic supervisors highlights any areas of transgression influencing findings at an early stage.

Open coding, axial coding & constant comparison

Open coding

Open Coding is used to code interview data into the widest variety of categories possible including those not explicitly stated, the intention being to generate emergent category sets that are workable and bear relevance for pre-dialysis education and treatment decision-making theory (Glaser 1978). Genuine open coding of pre-dialysis participants articulated views, aimed to counter any preconceived notions the researcher may hold. Thus, minimising the potential to force or distort the meanings derived from the data.

The analysis of open coding illuminated the study direction. Following the first interview and transcription review, data was open-coded to allow the underlying concepts to be explored (Wainwright 1994). To achieve this, fragmented data was examined so comparison between interviews could begin to develop concepts and categories (Corbin & Strauss 2008). Fracturing and reconstructing of data made possible its elevation to a conceptual level (Norton 1999). Fragmentation aided recognition of the interconnections and properties connecting codes, making possible their identification as dimensions of a broader phenomenon (Strauss & Corbin 1990).

Axial coding

Open coding went hand-in-hand with axial coding and occurred concurrently. Data was broken down into its constituent parts by open coding and then axial-coding could proceed to make connections between codes and formulate categories. The relating of concepts to one another reconstructed the data by linking cause, consequence and context to codes (Bryman 2008). In this process the conceptualisation of the participant experience became more abstract and moved away from basic open coding (Worked example, page 244).

Constant comparison

The cornerstone of grounded theory is constant comparative analysis. Utilisation of constant comparison analysis informed the adaptation and re-

formulation of interview topics, based on the concepts emerging from initial interviews. By returning to analysed data the concept intricacies associated with the pre-dialysis journey were enriched (Wainwright 1994).

The validity of grounded theory research analysis lay in the fair representation of participant response, which could be achieved by ensuring the results were developed from the data collected. The constant comparison of data attracting the same codes, aimed to challenge the developing codes and assess the need for new ones or sub-codes, until the developed coding framework fitted all of the data. The inclusion of rich data were crucial, as quotes and responses make real and confirm, or otherwise, the explanations being derived. The input of secondary data coders, the researcher's academic supervisors, ensures reliability. By independently analysing the first three interviews and discussing the coding and emergent themes it is possible to assess the level of agreement between the researcher and her supervisors coding. The extent to which codes are reliably applied is central to the trustworthiness of the analysis.

As categories became saturated during the coding process connections emerged about pre-dialysis education and the influences impacting upon treatment decision-making. The iterative process of going back and forth between data and emerging concepts, and the collection of further data to support or disconfirm concepts ultimately lead to substantive theory creation (Corbin & Strauss 2008).

Coding Reliability

In addition to independently analysing then comparing the first three transcripts, reliability testing of a randomly selected sample of transcripts was required; to ensure that the final coding framework was applied in a reliable, consistent manner. Reliability in interpretation is an important issue and ensuring application of a generated coding framework in the same way by all coders involved, was an on-going process. Awareness of interpretation bias through the researcher's reflexive and reflective practice and analysis of the agreement between separate coders aimed to minimise the effect.

Memos

Memos provided a written record of analysis so that trains of thought and thought progression were documented and could be reviewed and indeed amended throughout the analysis process (Corbin & Strauss 2008). Memo writing was useful to connect the threads running through individual, as well as the wider, data set. Initial concepts and links could be explored and a record of analysis was created. The decision-making process behind the study direction was evidenced and highlighted the researcher's modified view of the data and project overall (Smith & Biley 1997, Wainwright 1994). Critically, memos allowed the consideration of alternatives and concept establishment through an explicit thought process (Smith & Biley 1997).

Theoretical Saturation of Categories

Data collection in grounded theory research continued until theoretical saturation was achieved (Glaser 1978). Theoretical saturation results, when having collected and interpreted data about a particular category, it becomes saturated with data and no further knowledge is gleaned. Implications for the coding of data were that diminishing returns become evident with time, and data fails to add to category understanding (Bryman 2008). The failure of new data to illuminate a concept could only result when categories and concepts were fully developed and there was continuing emergence of the same properties (Glaser 1978). It is however crucial that the properties and dimensions of a category were not only well developed but that variation was demonstrated and that category relationships were well established and as a result, validated (Corbin & Strauss 1998).

Computer Software

The grounded theory data analysis was supported by the researcher's use of the NVivo (QRS International 2007, 2009) computer software programme for qualitative data analysis. Developments in computer technology, particularly over the last decade, have lead to a revolution in the capacity of programmes to enhance the analysis process and their recognition as mainstream tools.

The major benefit were the organisation, storage and retrieval of large volumes of data and provision of a clear audit trail of decision-making. NVivo 7 & NVivo 9 (QRS International 2007, 2009) retain and facilitate the coding processes traditionally associated with qualitative data analysis, but also

make possible the reorganisation of data analysis in different ways. The interpretation, coding and retrieval of data continued to be performed by the analyst (Corbin & Strauss 2008).

Conclusion

The exploration of the pre-dialysis journey, with its associated educational input and decision-making processes, was arguably suited to a Straussian approach. Unstructured interviews provided the opportunity to explore and understanding the influence of pre-dialysis education on treatment decision-making, in the Modelling Phase of this study. Data collection and analysis aimed to generate substantive theory. The emergence of themes gave a clearer depiction of the pre-dialysis journey. Analysis of those themes elucidated the specific elements beneficial to individuals' pre-dialysis journey and treatment decision-making.

Chapter Five: Methods

Chapter Five: Methods

Introduction

In this chapter details of the overarching ethical principles in operation throughout the research are discussed first and include: ethical approval, professional guidelines, informed consent, non-maleficence, confidentiality, research proposal terminology and funding bias. The chapter then proceeds to detail how the MRC Complex Intervention Framework: Modelling Phase methods, employed to implement and explore the impact of participants' pre-dialysis educational experience, were operationalised. The methods for the Modelling Phase are presented in two distinct sections:

- Section One: Participant Action Research Study
- Section Two: Service Users Pre-Dialysis and Treatment Decision-Making Experience: Grounded Theory Study.

Study aims, study design, population, data gathering and data analysis are identified for each study. The procedures taken to ensure that study results are trustworthy are set out.

Overarching Ethical Principles Applied to all Studies

Ethical Approval

An application was made through IRAS to Solihull Ethics Committee, reference ((09/H1206/82). The proposed research study received National Research Ethics Committee approval and subsequent Research & Development approval from the study site (Appendix 2). Academic supervision from the University of Warwick and clinical supervision from study site has overseen the conduct of the study. The researcher is also guided by the ethical and professional codes of conduct pertaining to the nursing, studying and research aspects of their work (MHRA 2005, NMC 2008,

http://www2.warwick.ac.uk/services/rss/apply_funding/ethics_governance/statement/guidance/ethicsguidance.pdf [accessed Feb 2008]).

Informed Consent

In this study all potential participants were approached in person by the researcher. HCP participants were approached in the work environment on a one-to-one basis. Patient participants were approached when they were attending pre-dialysis clinic, but after they had seen the clinician. The researcher explained the study; an ethics approved Participant Information Sheet (Appendix 3) and the reason for their invitation to participate was explained; reassurance was given that there was no obligation to participate and that non-participation would not affect healthcare provision in any way.

Potential participants were given two weeks to consider the study and were provided with the researcher's telephone and e-mail contacts, should they have concerns to discuss or questions to ask. Prior to the first PAR meeting or interview commencement, written consent was completed by all participants and a copy supplied to each individual (Appendix 4). Informed consent for non-English speaking participants was obtained utilising translators employed at study site or a third party of the participant's choosing.

In order for participants' to give informed consent, they were made aware of why the interview was being recorded, how the recording would be used, its storage, transcription and the destruction of the recording. Methods for anonymising data were explained. Confidentiality was imperative throughout the research process and participants needed to have confidence in this process, if they were to feel confident enough to participate.

Non-Maleficance

Though pre-dialysis education as a topic per-se may seem innocuous enough, any use of interviews has the potential to raise distressing and sensitive issues. To achieve the ethical principle of non-maleficance, "first do no harm" (Beauchamp & Childress, 2001), the researcher possesses person-centred counselling training, is an experienced senior renal sister and was able to recognise when individuals potentially required referral to fellow healthcare professionals. Assurance of information confidentiality was given and participants were reminded of their right to withdraw from the study at any point. On a more practical note, participants were shown how to stop the

digital recording, to give them a greater degree of control in the interview process. All participants were offered a summarised transcription of their interview.

Confidentiality

All data produced as a result of the study was stored on password-protected computers or an encrypted and password protected memory stick. Computers and memory sticks were further protected by their location in a suite of swipe card-protected offices. Computer use at the University of Warwick and the researcher's home computer were in secured locations and were also password-protected. Digital audio-recordings were downloaded and stored on password-protected computers; original copies were then deleted from the digital recorder following their transcription. An encrypted memory stick was used for the transfer of data. Field notes and diaries were kept in secured cupboards within the researcher's office at the study site.

Intervention participants and action research participants were allocated a study number when they enrolled for the study. A list of participants and study numbers was stored in a password-protected file, separate from the study data. Thus, all audio and transcribed data were anonymised. Generated qualitative data were anonymised to protect participant confidentiality. The level of confidentiality protection described was in accordance with academic institution, ethics committee and research & development department guidelines.

However, the potential exists for staff to be identified from quotations. Due to participants' specialist roles and the limited number of HCP involved in the

PAR, all quotes that could potentially identify individuals were checked with them prior to use.

MRC Modelling Phase: Research Summary

The rational for a two-method approach in this study, was to facilitate the introduction and modelling of pre-dialysis educational components and then to explore the impact of the pre-dialysis experience upon individual patients' treatment decision-making. The research methods employed are:

Section One: *Participant Action Research Study*: September 2009-March 2011

An Action Research Group was created to introduce theory-based pre-dialysis education into multidisciplinary practice. This phase continued for 18 months.

Section Two: Service Users Pre-Dialysis and Treatment Decision–Making Experience: Grounded Theory Study: January 2010-December 2011

Pre-dialysis experience and educational component impact was explored through interviews with 20 pre-dialysis patients. Interviews were conducted at three time points with each participant, as follows.

The overall structure of the research is presented as a study flow chart in Figure 5.0.0

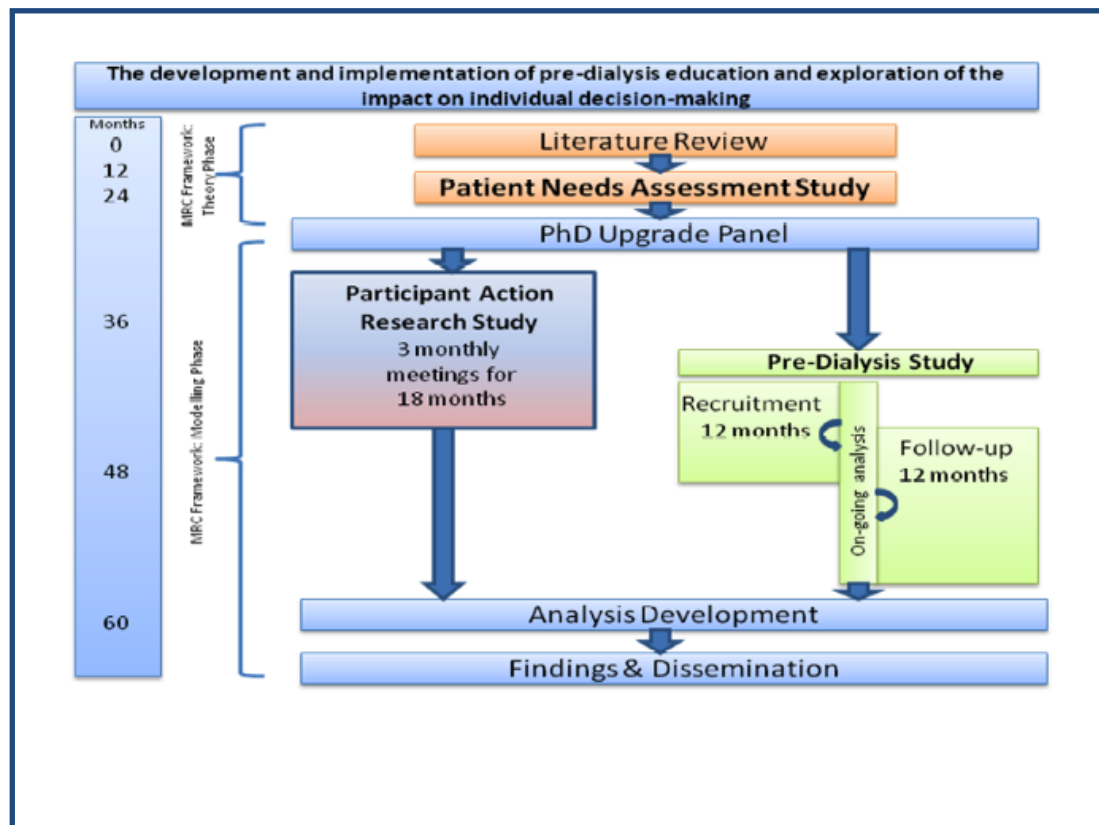


Figure 5.0.0 Study Flow Chart

Section One: Participant Action Research Study

Introduction

The first part of the methods chapter describes the Participant Action Research (PAR). The aims of the PAR study are followed by a definition of the action research typology and the way in which this was employed in practice. The study design identifies; timescale, research site, participants and resources. Finally, an account of the data gathering and data interpretation concludes the action research section.

Aims of the Participant Action Research Study

The study aimed to explore the following research questions:

- What should a learning theory and health policy informed pre-dialysis education intervention comprise?
- Who should deliver pre-dialysis education, what intervention components should be delivered and how should they be delivered?

A PAR methodology was selected to unite diverse stakeholders in a common endeavour to improve pre-dialysis education provision. Motivation to act was based on resolving to improve pre-dialysis education and each member of the PAR had the potential to influence proceedings.

Study Design

The Participant Action Research study commenced six months prior to the grounded theory study. Meetings were held 3 monthly, over an 18-month time period. Participants were recruited from the research study site's renal multidisciplinary HCP's and the service users attending renal outpatient clinics. Meetings took place on-site, in a non-departmental environment. Participants were provided with stationery, beverages and patient car parking was funded. Patients were not remunerated for their time. Homemade cakes were provided by the facilitator at each meeting, allowing a natural break to be incorporated into the meetings and aimed to confer a message about care, commitment and an honest appreciation of those involved (Taylor et al 2000). All cakes were 'renal friendly' (low in potassium) showing an obligation to group member inclusivity.

Study population

The action research participants were invited from members of the multidisciplinary renal team, who were already involved in the education of pre-dialysis and dialysis patients. Recruitment focused on individuals who were experienced and had expertise in the field of renal patient education. With a limited number of planned meetings available it was crucial participants had an existing knowledge of, and involvement with, the pre-dialysis education situation. The multidisciplinary diversity of the recruits and the inclusion of expert renal patients provided a range of perspectives, experience and approaches. The participants included are listed in Table 5.0.1

| |
|--|
| Action Research, Participants |
| Pre-Dialysis Clinical Nurse Specialist 1 |
| Pre-Dialysis Clinical Nurse Specialist 2 |
| Renal Dietician |
| Renal Psychologist |
| Renal Dialysis sister |
| Renal Social Worker |
| Patient Information Librarian |
| Transplantation Sister |
| Current Pre-Dialysis Service User |
| Current Transplanted Service User (previous HD, PD experience) |
| Renal Nurse Researcher |

Table 5.0.1 Action Research Participants

Representation from the pre-dialysis patient population was of paramount importance within the collaborative group. Diverse patient experience was sought in the patients consenting to collaborate. Individual participants' expertise contributed to the PAR through diverse understanding of pre-dialysis education and the integration of wide-ranging knowledge and experience. Patient collaborators were met individually to discuss their expectations of the research and afforded the opportunity to explore concerns and allay any fears in a less formal environment. All participants received an ethics approved Study Information Sheet and the opportunity to discuss any concerns was afforded prior to informed consent completion.

Data Collection & Data Analysis

The Needs Assessment Study and Literature Review findings were presented to the collaboration and their implications for education development discussed. Participant action research meetings provided a forum allowing individuals experiences of component implementation to be

described and qualified. These could then be interpreted within the context of component use and application.

Data Collection Opportunities

Participant Action Research Meetings provided the data presented in Tables 5.0.2, 5.0.3 and 5.0.4.

| |
|--|
| Minutes of meeting taken; decision-making recorded; minutes reviewed by collaboration for agreement; critical feedback encouraged. |
| Meetings audio recorded for reference checking and clarification of issues. |
| Reflective and reflexive diary maintained throughout by the researcher to record the researcher's thoughts and observations. |
| Discussion of issues and ideas with a critical friend (CNS 1). Diary documentation of discussion outcomes. |
| Validation group feedback on developments and reports for meetings. documentation of discussion outcomes. |

Table 5.0.2 Participant Action Research Meetings

One-to-one meetings were utilised to establish issues for exploration on a personal level prior to group consideration, and these are documented in Table 5.0.3

| |
|---|
| Field note data were recorded and checked with individuals prior to inclusion in PAR meetings. |
| Reflective and reflexive diary maintained throughout the research to record the researcher's thoughts and observations. |
| Issues raised were fed back into the following PAR meeting or followed-up in a one-to-one meeting, as agreed with the individual. |

Table 5.0.3 One-to-One Meetings

A reflexive and reflective diary was kept by the researcher and the type of diary entries are recorded in Table 5.0.4

| |
|---|
| Diary entries were made in a personal reflexive and reflective diary as an on-going process of personal and process evaluation. |
| Diary entries related to: <ul style="list-style-type: none"> • Issues and considerations: e.g. personal influence, power differentials, group tensions, effect and ineffective facilitation techniques. • Disagreement. • Process development. • Personal influence on the research process. • Influence of others on the research process and others people. • Ethical concerns. |

Table 5.0.4 Reflective & Reflexive Diary

The data illustrated were gathered systematically so that any changes instituted could be tracked and the on-going PAR process evaluated. Initial evaluation focused on the practicalities of changes made to education input, in terms of how and what was delivered. The group's findings and implications for practice were interpreted and then based on the conclusions drawn actions were generated. Thus a decision trail was created, to enable key points in the cyclical process to be identified, and, if required, revisited. In this way the analysis and interpretation derived from the meeting was taken back into the educational intervention, implemented over the subsequent 12 week period and further experiences brought back to the next action research meeting. This process was one of collectively and continuously acting on reflection and reflecting on action, for the duration of the study.

The cyclical nature of action research aimed to allow the knowledge and skills that pre-dialysis educators need to emerge, so indicating where gaps between theory and practice exist. It was proposed that the action research group would implement small changes and trial existing renal education components. These could then be evaluated from a service provision perspective. Evaluation of the usefulness of the trialled educational components was to be derived from the patient perspective in the form of interviews. However, it was acknowledged that the true collaborative decision-making employed in PAR, means that the process could not be predetermined, but agreed by collaborative decision-making.

Analysis of the researcher's facilitation skills was through reflective and reflexive diary use, and is incorporated into the PAR results (Chapter 6). Ultimately, some processes were unsuccessful, while others were effectively implemented. In this way, the influences on participants' pre-dialysis journey emerged from successful learning, reflection and the action cycles developed during the research.

Trustworthiness

The ethical principles of beneficence and justice, according to Beauchamp & Childress (2001), are realised in a study's honest and validated interpretation of research findings and their representation for dissemination. As the action research collaboration developed, a critical colleague with valued opinions and expertise was sought to critique the researcher's work and enlighten considerations. In addition a validation

group was convened to scrutinise progress data. This small group of three HCPs from the collaboration provided professional judgements on the researcher's summaries and recommendations (McNiff 2002).

When the action research was concluded, a summary of the collaborative work, utilising the Newton & Burgess's (2008) Validity Framework was produced. This was presented to co-collaborators for honest and critical feedback. The validity of the interpretation of the action research process and outcomes were then open for discussion. This took the form of anonymous feedback as this was felt to be appropriate and provided the best opportunity for honest feedback with impunity. Individual feedback from PAR members expressing their views in one-to-one conversations formed part of the reflective diary keeping.

On-going feedback of findings from the interviews was communicated to participants involved in the action research via presentations and newsletters. This was part of a wider strategy to feed back progress and findings to all participants and a wider audience, and is explained in more detail in the Grounded Theory Section of this chapter.

Conclusion

This section sets out the action research methods employed in accordance with PAR (Cohen & Manion 2007). The research aims, design and study population are identified. The data gathering and analysis methods have been presented. The chapter continues by presenting the grounded theory method. The PAR results are presented in Chapter 6.

Section Two: Service Users Pre-Dialysis and Treatment Decision-Making Experience: A Grounded Theory Study (Pre-Dialysis Study)

The Need for Pre-Dialysis Education Delivery Theory

Drawing on the views and experience of individuals can develop theories of pre-dialysis education delivery as they progress through the pre-dialysis period. Additionally, literature review evidence can be used to compare findings. HCPs delivering pre-dialysis education have extensive knowledge of their own field; however as Puolakka et al propose:

“A substantive theory illustrating and explaining social action can help those who are experts in their respective fields to examine their working environment from an angle that is not obvious”. (Puolakka et al 2013)

The opportunity to explore and reflect on the insight of others that would otherwise be unknown, progresses practice to a conceptual level and findings can then be generalised (Corbin & Strauss 2008).

The Pre-Dialysis Study aims are presented and followed by the study design plan. Study design identifies; participant and study timelines, the study population, inclusion and exclusion criteria and participants identification and recruitment. An account of the data gathering is described. Data collection and data analysis are presented as a worked example.

Aims of the Pre-Dialysis Study

The aims of the interviews were to understand:

- What influences individuals' self-efficacy and helps them to cope and adjust, over the pre-dialysis period?
- How does a pre-dialysis educational intervention affect individuals' decision-making about their dialysis treatment choice?

Study Design

The unstructured interviews identified an area of interest for exploration, namely the participants' experience of the pre-dialysis journey. However, the researcher without pre-determined questions entered into interviews. To fulfil the requirements of the Ethics Committee Review the areas of interest and potential topics were submitted (Appendix 7).

A deeper understanding of the factors influencing participants' pre-dialysis journey, education and treatment decision-making, from a personal and service provision perspective, was sought. The longitudinal design of three-interviews over the pre-dialysis year, aims to capture influences and their impact, and the way these change over the pre-dialysis period, to better understand the timing and impact of education provision and treatment decision-making.

Patient and Public Involvement

Critical feedback on all potential interview topics, from a selection of respondents similar to, but not part of the research group was sought. The

local Kidney Patient's Association (KPA) were keen to be involved with the study development, after agreeing to fund car parking charges for patients attending the re-modelled pre-dialysis education day. The researcher was able to attend their association meeting and discuss their pre-dialysis memories and service user experience. To fully engage with the KPA and their members the researcher wrote an article for their local patient magazine 'The Kidney Kourier' and sent study up-date newsletters to the local KPA, as well as participants. The researcher asked patients attending a pre-dialysis education day if they would review potential interview topics for appropriateness. Verbal feedback from attendees confirmed that the topics were appropriate and pertinent. These topics formed the basis of the approval sought from the ethics committee.

Interview Timeline

Participants in the study were drawn from the pre-dialysis clinics held between September 2009 and September 2010, run by the nephrology consultants and clinical nurse specialists (CNSs). Interview follow-up continued until December 2011. Participants were asked to consent to complete three interviews. The first, baseline interview, followed their initial referral to the CNS, with subsequent interviews at six months following baseline, and at one-month post treatment commencement, or at twelve months if treatment was not imminently required. Interviews were audio-recorded and transcribed verbatim by the researcher.

Participant Identification & Recruitment

Potential interview participants were identified from the PROTON renal patient computer database at the study site, by the researcher. PROTON stores demographic data, forthcoming clinic dates, a timeline and medical data on all nephrology patients under the care of the study site nephrology team.

Though patients were identified through the PROTON system it was the judicious selection of participants, by their characteristics of interest, which facilitated theoretical sampling and ultimately exploration of their pre-dialysis experience to identify congruent and divergent views.

Study Population

The intention was to recruit twenty individuals from the pre-dialysis clinics at the study site. The clinics help manage the patients' renal disease and prepare them for dialysis, transplantation or conservative management, as they approach end stage renal failure. End stage renal failure is the point at which an individual's renal impairment has reached a critical level and active treatment is required to preserve life. Participants were theoretically sampled from those individuals whose Glomerulofiltration Rate had fallen below 30mls/min/1.73m² and who were estimated to require commencement of dialysis within 12 months (NSF for Renal 2004, NICE 2008). Baseline interviews were completed at this time point. All patients referred to the pre-dialysis clinic during this data collection period could potentially receive the interventions implemented by the Action Research Group. This was dependent on individuals' actual and perceived

educational need and the individual care pathway instituted by the Nephrologist.

Inclusion & Exclusion Criteria

Inclusion criteria were:-

- A glomerulofiltration rate (GFR), the indicator of the patients' degree of renal failure, of $<30\text{ml/min/1.73m}^2$ in patients who are expected to start definitive treatment for ERF within 12 months.
- Patients over 18 years of age, and ability to give informed consent.

Exclusion criteria included:-

- $\text{GFR} >30\text{ml/min/1.73m}^2$ and individuals not expected to start dialysis within the next 12 months (slow rate of renal decline).
- Patients under 18 years of age and those who are unable to give informed consent.
- Individuals in the final pre-dialysis stage of preparing for treatment commencement, within the following six months, were invited to participate in the piloting study.

It is important to note that predicting the rate of renal decline is complex and fraught with complicating factors, and is accordingly an imprecise science. Multifarious, known and unknown, factors influence renal decline (Goldstein 2004, Lenz 2005). Indeed a myriad of potential influences exist that make estimation of treatment need as much an art as a science. Therefore, referral is at best an estimate based on the renal disease profile, individual

biochemistry and the nephrologists' judgement based on extensive experience and expertise.

Data Collection

In accordance with grounded theory methodology unstructured interviews were conducted with individuals in the pre-dialysis phase of renal failure (CKD Stage 4). In reality data collection and data analysis went hand in hand, with emergent themes guiding further data collection through theoretical sampling.

In practical terms interviews were arranged with individuals once they had agreed to participate. The date, time and location of the interview were agreed and a confirmation phone call the day prior to the interview was offered. This allowed participants to amend or cancel the appointment if inappropriate, without having to worry about contacting the researcher. Equally, it was a reminder that the researcher would be visiting the following day and thus reduced the risk of missed or forgotten appointments.

Interviews were fully transcribed as soon as possible following the interview to maintain clarity of understanding and nuance. All interviews were transcribed within three days of the interview and wherever possible the same or next day. Additionally participants' treatment status was verified and recorded on a monthly basis, to detect changes and to ensure interviews were conducted in a timely manner should participants' treatment circumstances change.

Data Analysis

Following data collection the first step was to listen to the interview in its entirety. The data were transcribed using a dictation software programme (Dragon Speaking Naturally 2009). This involved: listening to short sections of audio recording, pausing the play back, and verbally repeating the passage. All software dictation transcripts were checked for accuracy as transcription progressed. The verbalisation of participants' narrative brought a different focus to statements as they were repeated. Repeating rather than typing the narrative helped to increase submergence in the data.

Once the transcription was completed time was invested in re-reading the narrative and then open coding and microanalysis, to understand the data. If considered alone, microanalysis had the potential to break meaningful statements down into a series of analysed but unconnected snippets of information. Conversely, in this study it helped to facilitate consideration of the use of language and individuals phraseology for unspoken messages (see Open coding example, lines 1 & 2, page 245). However, these needed to be understood within the context of the wider interview data. Use of memos, constant comparison and axial coding helped to develop the links between microanalysis findings and category formation that fed into the emergent themes.

Memo writing provided a written record of the data analysis. Recording the flow of thoughts helped to increase the open coding analysis depth and facilitated the process of constant comparison. This was particularly important with theoretical sampling resulting in recruitment over a twelve-

month period. The on-going analysis and memo writing facilitated retracing of the analytic process as well as constant comparison.

Worked Example

It may be useful at this point to provide a worked example of data analysis. The examples are taken from the first two interviews conducted and include open coding, constant comparison illustration, axial coding. Within the memo itself theoretical sampling direction is identified.

Figure 5.0.5 highlights the open coding, constant comparison and axial coding associated with a section of narrative from the first interview participant. The memo relating to the same data provides greater insight into the analysis and thought processes of the researcher.

Figure 5.0.5 Coding example for open coding, constant comparison & axial coding

Open Coding (by Line)

Questioning need..... “If it has got to be done [dialysis] the important
Survival..... thing to me is that I keep going. That’s the
Re-iterating emphasis on survival... important thing to me. This is really how I go on
Established coping mechanism..... you see, we’ve had Christmas then it’s my
Goal setting..... birthday in March and then kids birthdays then
Family support/supporting family... our wedding anniversary, so that’s how we get
on with it”.

Constant Comparison

Shift in the location from
 self, to part of the family.
 Narrative goes from “I” to
 “we”. Indicating the
 strength of family support.

Axial Coding

Goal setting is an
 established Coping
 Mechanism and this
 supports Survival.
 Also feeding into the
 need for survival is
 the bi-directional
 nature of Family
 support and
 Supporting the family.

MEMO: Worked Example

MEMO: Worked Example

During the first interview this man told his story of discovering his renal failure and his prior long complex history of extensive and life threatening cardiac events including multiple cardiac surgery. At the following point in his narrative he reflected on his priorities relating to his health status.

“If it has got to be done [renal replacement therapy] the important thing to me, is that I keep going. That's the important thing to me. This is really how I go on you see, we've had Christmas then it's my birthday in March and then kids birthdays then our wedding anniversary, so that's how we get on with it”. (Male, aged 76)

The following excerpts are from the memos written by the researcher during analysis:

As he reflects on how he deals with the need for renal replacement therapy, he describes how he uses goal setting and achieves this through the use of family milestones. The importance of family is emphasised as his description of keeping going moves from singular ‘I keep going’ to plural ‘we get on with it’. A united coping strategy may be indicative of a family experienced at coping with his health problems. It also defines the properties of family support, as well as, support for the family. As a patriarchal figure he is locating himself in terms of the family dynamics. This may be an important motivator for ‘keeping going’.

'Keeping going' appears to be the imperative and is identified as the 'important thing' and reiterated. Being there for family seems to be a driving force for survival. This may relate back to his extensive experience of life threatening illness, over an extended period of time and from a young age. He has extensive experience of healthcare professionals and healthcare utilisation. I wonder has this honed his ability to cope and adjust to changing levels of health? Have previous positive healthcare outcomes given him the confidence to face future healthcare challenges? Or does the concept of disease weighting (cardiac issues perceived to be more important 'bigger'), based on prior experience, indicate a degree of doubt in the need for renal replacement therapy i.e. "If it's got to be done". Do such major and life threatening cardiac events overshadow the severity of renal failure, especially when renal symptoms may not yet be evident? Within this narrative sample the thread running through the data seems to be 'survival' and the elements of family support, goals setting and healthcare experience feed into this.

Memo Reflections

This led me to consider, is survival the central focus during the pre-dialysis period and if so how does prior healthcare experience influence coping mechanisms? The direction of Theoretical Sampling was guided by the following question: In other individuals experiencing the pre-dialysis journey, without prior major life threatening illness, does survival feature as strongly? This aimed not only to extend understanding of survival in pre-dialysis

individuals but also to look at how the concepts of 'coping' and 'family support' relate to each other.

Directing theoretical sampling

Data collection therefore proceeded by recruiting an individual without prior serious healthcare problems and comparisons were made at a concept level with the first participant. The second participant had Polycystic Kidney Disease (PCKD) and had been seen in renal clinics for twenty years, since first diagnosis. She had no comorbid conditions and no renal failure symptoms and was, in her view, living a fit and healthy lifestyle. The same process of breaking data down into sections and examining the data was employed. Some of the data were coded using the same conceptual name and this offered an extended insight and understanding.

Throughout the process of open coding and constant comparison the act of axial coding was on-going. Axial coding was an integral part of narrative analysis from the start, as the connections between and influence of one concept upon another, i.e. survival and experience, grew from the data. The discussion of two concepts within the memo illustrates the connected nature of the analysis process. This process continued between participant data and led to amended connections with increased insight, gained through the understanding of another.

With developing agreement and diversity in participants' narrative the properties and dimensions of the categories built. The desire to understand

the pre-dialysis experience remained the focus; however it was the concepts emerging from the interviews that continued to direct the theoretical sampling process.

Theoretical Sampling Direction

After the second interview, concepts were added to and new concepts emerged. The second participant's interview centred heavily on experience, but this time it was 'vicarious learning. Extensive familial experience of her mother and sisters treatment for PCKD and their renal replacement therapy featured strongly in her reflections and treatment decision-making process. Therefore, subsequent theoretical sampling sought another participant with familial vicarious learning, to further compare and contrast for concept development.

As theoretical sampling and data analysis progressed the impact of renal vicarious learning began to feel like an important factor in individuals' pre-dialysis experience. In addition, the findings from the earlier Needs Assessment Study had suggested that individuals had both positive and negative vicarious learning. I wanted to explore individuals' perceptions of vicarious learning and how this influenced their treatment decision-making.

Theoretical Saturation

With each subsequent interview the properties and dimensions of concepts and emergent themes were developed. Understanding of the pre-dialysis journey experience from the perspective of those living through it grew. Continued coding developed emergent themes and introduced new concepts

and provided amended and new links between existing concepts. The process of coding each interview before proceeding with further theoretical sampling enriched the data collection.

One could not possibly know the range of questions required to understand the pre-dialysis experience prior to initial data collection and how enquiry would evolve. Throughout the study, sampling progressed on the basis of emergent themes. The Pre-dialysis study took just over a year to recruit twenty participants by means of theoretical sampling. The added benefit of the extensive recruitment period was time to reflect on analysis, to reflect on the concepts and their inter-relationships. This allowed the diverse range of pre-dialysis experience to really sink in and avoided superficial analysis:

“It takes being immersed in the materials for some time before the significance of what is being said comes through” (Corbin & Strauss 2008 p230).

With vicarious learning emerging as such a powerful influence as sampling continued, understanding the context and the link with treatment decision-making was important. Therefore, in the follow-up interviews I looked specifically for circumstances where vicarious learning was influential. Additionally, follow-up interviews facilitated analysis of not only historical but also contemporary vicarious learning. Follow-up interviews added insight into the experience of the education delivered, following the remodelling of the education day, which included peer presenters offering vicarious learning. An example of how statements were categorised and concepts were used to

name categories is presented in an Example of Statement Classification in Table 5.0.6

Table 5.0.6 Example of statement classification

| Categorised statement | Concept | Category |
|---|---|---|
| Consistent care delivery team. Trusted source of information. High workload and limited time. Treatment of condition not the individual. Preconceived notion of Dr/patient roles. Paternalistic patient care. | Nephrologist clinic experience. | Delivery of pre-dialysis education in the clinical setting. |
| Listening and discussing, communication. Trusting supportive and empathetic. Assessment of patient need, patient lead consultation. Consultation timing. Building on understanding. Working in partnership. Preconceived notions of doctors and nurses roles. | Experience of clinical nurse specialist clinics. | |
| Building tailored education delivery. Diverse use of education sources and delivery methods. | Clinical nurse specialist education delivery adaptation. | |
| Negotiation of shift in primary/secondary care delivery. GP's cede responsibility to nephrologist. Communication failures. CNSs problem solve. | Shifting care emphasis in the primary/secondary care interface. | |

Secondary Coding

The use of secondary coders to ensure analysis agreement was employed. The first three interviews were independently open coded and analysis discussed by the researcher and both her academic supervisors, to establish interpretation concordance. The themes emerging from the interviews and

the impact on sampling direction were discussed. However, subsequent reliability testing of a randomly selected 10% sample of transcripts ensured codes were reliably applied to ensure the trustworthiness of the analysis. Ensuring coding agreement by all involved was an on-going process.

The researcher's use of an interview journal post-interview, and post-transcript analysis, aimed to develop self-awareness through reflection on practice. A summarised copy of the participants' transcripts was offered to all participants to increase the reliability and trustworthiness of the data interpretation further. On completion of the Grounded Theory analysis, emergent themes resulted in a conceptual model to fit all the data. The pre-dialysis grounded theory conceptual model is illustrated and discussed in the grounded theory results chapter (Chapter 7, p 390).

Dissemination of findings

Diverse dissemination of initial study findings through conference presentations and professional forum presentations and specialist group newsletters was achieved. A simple research newsletter was produced on a six-monthly basis to keep participants informed of; study progress, initial developments, findings, dissemination of data and to encourage continued participation. Newsletters were posted to all participants involved, once their health status had been identified (Appendix 5 Example Newsletter).

Conclusion

Data analysis using Grounded Theory has provided a method to understanding individuals' and the wider cohort's pre-dialysis journey comprehensively. The Methods Chapter has presented the overarching ethical considerations. The Participant Action Research and Pre-Dialysis Study components of the research have been described and examined individually. A worked example provides evidence of the analysis process. The procedures taken to ensure study results are trustworthy have been set out. It is this attention to detail in the method that allows the participants' pre-dialysis stories to be told and original knowledge related to educational input and treatment decision-making to be established in the analysis of findings.

Chapter Six:

Participant Action

Research Results

Chapter Six: Participant Action Research Results

Introduction

The aims of the Participant Action Research (PAR) was to implement and qualitatively evaluate pre-dialysis educational components and identify the knowledge and skills required for effective facilitation and development of an educational intervention. The findings from the Literature Review and Needs Assessment Study inform the PAR Study development.

The PAR collaboration worked over an 18-month period to review and make changes to the pre-dialysis education delivered at the study site. Seven meetings, held at 3 monthly intervals, provided the framework for group collaboration. The main change instituted by the PAR was re-modelling of the pre-dialysis education day. However, other smaller successful and, ultimately, unsuccessful changes were introduced and these are presented in summary tables at the corresponding meeting time point. This chapter is laid out in chronological order, through Meetings 1-7. A chronology of the action research meeting contents is presented in Table 6.0.0, to give clarity and explain the order to the changes instituted.

Action Research Meeting Chronology

| | |
|--|---|
| i) Meeting ii) Date iii) Attendees (n) | <ul style="list-style-type: none"> • Meeting Content |
| i) Pre-Preparation ii) May-Sept 2009 iii) 10 Participants Recruited | <ul style="list-style-type: none"> • Ethics and R&D approval. • Invitation to individual multidisciplinary staff delivered in person. • Participant Information Sheets supplied pre-meeting. • Individual meetings with both patient participants to discuss expectations and issues. • Power-point presentation to identify the: <ol style="list-style-type: none"> 1. PhD Research Proposal and how the action research fitted in. 2. Participatory Action research. 3. Barriers to action research. • Potential ground rules for consideration. • Consent form prepared. • Agenda sent |
| i) Meeting 1 ii) 09.10.2009 iii) 11 | <ul style="list-style-type: none"> • Introduction to the research. • Power point; PhD research, Participatory Action Research. • Discussion and questions on proposal. • <i>Refreshments</i> • Power point; Barriers to AR, Benefits of AR. • Ground Rules discussion and consensus. • Frequency of meetings and future dates agreed. • Consent forms completed. |
| i) Meeting 2 ii) 04.12.09 iii) 10 | <ul style="list-style-type: none"> • Minutes from previous meeting • Presentation of Literature Review and Needs Assessment Study Findings. • Discussion: Potential education components to explore and introduce. • <i>Refreshments</i> • Patient education day review (flip chart, re-modelling) • Ethnic minority education provision discussion • Agreement of individual action points |
| i) Meeting 3 ii) 05.03.2010 iii) 7 | <ul style="list-style-type: none"> • Minutes from previous meeting • Feedback & Discussion on current education resources identified • Revised patient education session feedback (Clinical Nurse Specialists (CNSs)) • <i>Refreshments</i> • Continued education session review • Service Directory need identified • Agreement of individual action points |

| | |
|--|---|
| i) Meeting 4 ii) 11.06.2010 iii) 9 | <ul style="list-style-type: none"> • Minutes from previous meeting • Feedback on revised education session (multidisciplinary) • <i>Refreshments</i> • Service Directory development plan • Relaxation CD discussed • Agreement of individual action points |
| i) Meeting 5 ii) 08.09.2010 iii) 8 | <ul style="list-style-type: none"> • Minutes from previous meeting • Education day feedback • Services directory development progress • <i>Refreshments</i> • Relaxation CD presentation (Clinical Psychologist) • Agreement of individual action points |
| i) Meeting 6 ii) 08.12.2010 iii) Cancelled -10 degrees | <p>Electronic communication and Individual Meetings:</p> <ul style="list-style-type: none"> • Service Directory electronic review and feedback from AR collaboration. • Individual meeting with: <ul style="list-style-type: none"> ○ Psychologist to discuss relaxation CD issues. ○ Dietician to discuss pharmaceutical sponsorship of directory printing. ○ Patient Information Librarian to discuss directory approval and electronic availability. ○ CNS to review patient education day. ○ Liaise with individual renal departments for directory information. • Agreement of individual action plans. |
| i) Meeting 7 ii) 11.03.2011 iii) 9 | <ul style="list-style-type: none"> • Minutes from previous communications & individual meetings. • Renal Services Patient Directory final review. • <i>Refreshments</i> • Directory sponsorship and printing (Dietician) • Directory electronic availability (Librarian) • Conclusion of AR collaboration; <ul style="list-style-type: none"> ○ Review of achievements ○ Discussion about process ○ Agreement to continued informal support network ○ Agreement to continued up-dates and feedback on PhD research & patient evaluation • Thank you to all individuals involved |

Table 6.0.0 Action Research Meeting Chronology (Continued)

The PAR study was guided by the iterative action research cycle (Lewin 1946). The hierarchy of action research cycles is presented at the start of this

chapter as an overview, to clearly identify the cyclical process, and its association with meeting progression (Table 6.0.1).

Hierarchy of Action Research Cycles

| Participant Action Research Meeting | Action Research Cycle Stage |
|-------------------------------------|---|
| Meeting 1 | Reflective |
| Meeting 2 | |
| Meeting 3 | Planning Action Observe Review |
| Meeting 4 | Reflective Planning |
| Meeting 5 | Resultant Change On-Going Refection |
| Meeting 6 | |
| Meeting 7 | Observe Reflective Plan |

Table 6.0.1 Hierarchy of Action Research Cycle with Meeting Chronology

PAR meetings 1-7 are described, and the reflective and reflexive accounts presented. Developments of the researcher's PAR facilitation skill are explored. The validity of the PAR results is discussed. Ultimately, the pre-dialysis journey, and educational components utilised, are qualitatively explored with patients experiencing pre-dialysis education. These results are reported in the Grounded Theory Results Chapter (Chapter 8). This chapter

concludes by drawing together reflections on the experience of facilitating a PAR study, the challenges presented, and the benefits and pitfalls of the methodological approach.

Pre-Meeting Preparation

PAR Participant Recruitment

Reflection

Potential participants had been invited to engage on the basis of their patient education involvement, established experience and dynamic approach within renal services. Recruitment was straightforward and participants appeared keen to take part and expressed a motivation to improve education delivery. Only one individual expressed reticence to participate. However, they agreed to participate when the value of their experience and insight was highlighted. Subsequently, they dropped out after two meetings, citing increased workload. Exploration of further reasons for withdrawal drew no insight. This illustrates that even as an insider-researcher, knowledge of inter-departmental politics, with which you have no involvement, is limited. However, this distance from everyday departmental politics actively helped to reduce potential bias.

Reflexive

By selecting and inviting key staff and patients, the potential for service delivery to be developed and implemented successfully was deemed to be greatest. However, this selection process was divisive and negated the opportunity for new or 'quiet talent' to be utilised or discovered and nurtured.

An open invitation would not only have gauged service-wide interest, but also facilitated the involvement of those expressing an interest. It would also have avoided the potential alienation of those not invited to participate. There is a delicate balance between elite selection and community representation. The reality is that of facilitating manageable but more limited, versus a widely inclusive but unwieldy group.

As a novice facilitator with limited confidence, a small group of highly experienced individuals provided an ideal environment to develop the researcher's skills. At inception the changes to be instituted were as yet unidentified and there-in lies the difficulty of group formation prior to development agreement. Once key developments were established, it may have been wise to extend group membership to include those directly affected by the changes.

In addition, more information about the study aims, disseminated at the earliest opportunity to a service-wide audience, would have helped to; quash unfounded worries; address concerns raised and potentially have resulted in improved understanding and engagement from the wider community.

Meeting One

Focus in the first meeting was on establishing the PAR members as a group. An informal circular seating arrangement was used. Group members, including the facilitator, introduced themselves with their name, representative capacity and something about their everyday life and background.

ZK's introduction provides a typical example:

“I’m ZK. I’ve had renal problems since I was 17. I started on PD and then had haemo and my transplant was 5 years ago next week. When I started I don’t remember having any education. I’ve been going out to temples and community meetings to try and educate people about renal problems, so I’m really interested in this”

Members shared their experience of renal services, highlighting a diversity of knowledge and experience but also a central connection to our collective enquiry. Following introductions the key principles and practices of PAR were explained. Time was given to answer questions and discuss action research methodology. An overview of the PhD and the place of PAR within the overall study provided the bigger picture. The iterative process of reflecting, planning, acting and observing in a cyclical process was identified. Ground rules were created to establish a confidential, trusting and respectful foundation for group working.

Towards the close of the meeting potential ideas for educational components were identified by the group and listed for fuller exploration in the following

meeting. A suggestion for reviewing the pre-dialysis education day (ED) came from one of the Clinical Nurse Specialists (CNSs) responsible for its organisation and delivery. Also included in the list were a number of components suggested by the facilitator, based on a review of the renal and diabetes literature.

Reflection

The spectrum of experience, perspectives and value interests was diverse. However, there seemed to be an ease within the group to express opinions and be listened to. The declination of my clinical supervisor, a nephrology consultant, to join the group caused me considerable consternation, due to my lack of experience and indeed confidence to facilitate a group. My initial thoughts were somewhat anxious and I recorded:

Making this work [PAR] is down to me now. I really need to do some more detailed reading on group facilitation.

Given time to reflect on the situation and more importantly the principles of participant action research, my more rational response was: This is a collaboration and participants will be co-researchers. I still need to do a good job of facilitating the PAR but the other participants are experienced and bring with them a range of skills. It's the way individuals work as a group that will help the study succeed or otherwise.

With hindsight the situation was fortuitous. Whether through fate or design, and I suspected the latter, it would have had a potentially detrimental effect on the balance of power within the group and the resultant equitable group dynamics may have been lost.

Reflexive

At this early stage of the group's formation there was a potential for the components identified by the researcher to have undue credibility placed upon them, because of her academic status and initial position as group facilitator. The potential to bias future component selection became apparent on reflection. To regain the equality of influence, it was suggested by the facilitator in meeting minutes, that for the following agenda the inclusion of collaboration process maps, current education provision, might identify gaps and potential solutions. With positive feedback, process mapping formed the basis of the following meeting.

Meeting Two

Self-Efficacy Theory

The findings from the Literature Review and Needs Assessment Study were presented to the collaborative group. Particular attention was paid to the use of a theoretical foundation for the delivery of patient education. In particular this applied to, the benefits found to be associated with Self-Efficacy Theory (Bandura1977). Examples of self-efficacy promoting behaviours were supported with direct quotes, from the Needs Assessment Study, conducted at the same study site. The aim was to bridge the theory-practice gap by giving examples to which collaboration members could directly relate. Discussion of the Literature Review provided the opportunity to highlight the progressive Government Policies supporting self-management in patients with chronic long-term conditions.

The process mapping provided a focus and initial drive for the enquiry and created a clear picture of current practice. The CNSs defined how the pre-dialysis team had recently undergone radical changes. Staffing had increased from a single CNS to a team of five. The CNSs' team had already instigated an increase in the pre-dialysis education day delivery to monthly and opened up invitations to all study site renal patients.

All stakeholders expressed the importance of the education day in pre-dialysis preparation. The result was a unanimous agreement to review its format and delivery. Reviewing the education day within the PAR setting facilitated the inclusion of the main contributors to the education day. There

was a consensus amongst those presenting the education day that it was too long for patients to cope with, and was an inappropriate setting for the delivery of certain educative material. Subsequent patient evaluation feedback supplied by the CNS confirmed this view. We had the initial enquiry identified, namely re-modelling of the education day.

During the process mapping, ZK identified the lack of ethnic minority leaflets available for patients. With established links to Kidney Research UK, who have produced many such leaflets through their ABLE programme (A Better Life through Education); the facilitator was able to source a variety of evidence-based leaflets for review in the following meeting. Ethnic minority patient information leaflets introduction is summarised in Table 6.0.2

| PAR Process | Activity |
|--------------------|---|
| Issue Identified | <ul style="list-style-type: none"> • Lack of ethnic minority patient information leaflets. |
| Process & Lead | <ul style="list-style-type: none"> • Identify validated leaflets for review. • Facilitator to source leaflets from Kidney Research UK |
| Development Plan | <ul style="list-style-type: none"> • Facilitator to supply CNS team with patient leaflets for review. • CNS team to review leaflets and CNS PAR member to report back to PAR group. |
| Implementation | <ul style="list-style-type: none"> • Leaflets to be used as appropriate with pre-dialysis patients. |
| Review/Observe | <ul style="list-style-type: none"> • Usefulness assessed during patient interviews and reported back to PAR and CNS team. • CNS team to assess patient response to the leaflets. |
| Reflect & Plan | <ul style="list-style-type: none"> • CNS team member lead for ethnic minority information identified and links established through the facilitator with Kidney Research UK. • CNS negotiated with clinical director for leaflet |

| | |
|---------------------|---|
| | funding. |
| Resultant Change | <ul style="list-style-type: none"> • Improved provision of pre-dialysis written information for ethnic minority groups. |
| On-going Evaluation | <ul style="list-style-type: none"> • Annual review to ensure continued appropriateness of information. • E-resources for ethnic minority information on NHS Kidney Care website to be explored by CNS lead and patients advised accordingly. |
| Reflection | <ul style="list-style-type: none"> • A very simply facilitated provision of information that helped to establish PAR usefulness, efficiency and practical solution based philosophy. • Development of a lead within the CNS team increases the long-term commitment to ethnic minority patient education, once the PAR has finished. • Increased confidence of individuals to source and verify component validity having experienced the process. |

Table 6.0.2 Ethnic minority patient information leaflets

Reflexive

During the meeting the facilitator had purposely not suggested any specific components for consideration. Having expressed the view that the group members were the experts, the facilitator completed the scribing of flip-charts detailing the process mapping and subsequent exploration of individual opinions.

Reflection

At one point the discussion was dominated by the needs of one department and the pressure exerted by government guidelines, moving the subject way beyond the remit of the PAR group. It was patient participant ML who reined

in the discussion, by asking for clarification of the study's sphere of activity i.e. small local changes. ML's experience of effective meeting management helped to regain focus. Highlighting PAR parameters prevented a loss of purpose and direction. After the meeting, appreciation of ML's intervention was acknowledged. However, it was also important to understand the pressure and constraints upon the individual members and their departments, so a one-to-one meeting was arranged, with a view to exploring the issues affecting patient education delivery.

Though time was lost in the meeting, by acknowledging within the group the constraints of individual departments, willingness to understand them, even if unable to change them, was an important principle. It valued individuals and was realistic about limitations. This helped to build confidence in the group and facilitate participation.

Meeting 3

The main enquiry issue was identified, so focus turned to the development and evolution of the ED, through the action research process. With the purpose, form and direction initiated by the collaboration, the facilitator identified the current literature and guidelines recommending renal ED topics (NSF 2004) and formats (Costantini 2006, Inaguma 2006, Mason 2008). This information was circulated electronically to collaboration members for consideration prior to Meeting 3.

Consensus on the need to shorten the ED provided the starting point to explore re-modelling. The original format was written up on a flip chart, providing a clear layout for consideration. As the CNS organised and administrated the ED it was logical that they took the lead for the session, with extensive input from the whole group. Dialogue between collaboration members was facilitated through questioning and clarification. There was a consensus that certain sessions needed to remain. These included giving information about patient treatment options, anaemia and kidney failure.

New recommendations based on the findings of the Needs Assessment Study included the presence of an expert patient alongside the haemodialysis (HD) and peritoneal dialysis (PD) presenters, to discuss their experience and answer patient questions. Planned patient contact was found to have a positive impact, and was advocated by the needs assessment participants. The provision of such vicarious learning, or real patients' experience, received strong support from the expert patients who

championed the benefits. Collaborative agreement was based on the selection of appropriate patients by the CNSs. The original ED format was documented on a flip-chart with session timing, topic and then followed by collaborative evaluation of each component. This mapped the issues and the potential solutions discussed for implementation. This mapping is reproduced from the original flip chart in Table 6.0.3

Original Education Day Format

| Time | Topic | Evaluation |
|--------------|--|--|
| 09.00-09.30 | Introduction & Kidney Function/Disease and Anaemia | Session too long. Reduce the introduction and focus on kidney function rather than individual kidney diseases |
| 09.30-10.30 | Haemodialysis | Session too long. Need a real machine in the room not a picture. Need a HD patient representative at session to answer patient questions and give the patients experience. |
| 10.30-11.00 | Refreshment break | Provide refreshments in room so patient don't have to go down 5 floors to coffee shop and therefore get a proper break and can socialise with peers and staff. |
| 11.00- 12.00 | Peritoneal Dialysis | Session too long. Keep demonstration by staff. Need a PD patient representative at the session to answer patient questions and give the patients experience. |
| 12.00-12.30 | Transplantation | Session not appropriate for vast majority of patients. Important to highlight why individuals may not be able to have a transplant. Reduce the session to sign-posting. |
| 12.30- 13.00 | Kidney Patients Association (KPA) | Session too long and too personal (The renal patient representing the KPA discussed their own extensive experience. This may not be helpful and was then asking patients personal questions about their renal failure that may put attendees in an awkward/embarrassing position). Reduces to a sign-posting session. |
| 13.00-13.30 | Lunch | Break too short as many elderly/disabled attendees who need to have a rest and get food from the restaurant. Make the break longer and advise on bringing packed lunch for ease. |

| | | |
|-------------|-----------------------|---|
| 13.30-14.15 | Dietician | Session too long. Generic renal diet advice of limited use as each patient's results will vary. Reduce to a sign-posting session to introduce the dietetics service. |
| 14.15-14.45 | Social Worker | Session too long. Participants need to know the social workers are available and how to contact them. Reduce to a sign-posting session. Maybe combine with KPA. |
| 14.45-15.30 | Psychologist | Session too long and not applicable to all. Reduce to a sign-posting session to introduce the psychology services and how to contact them. |
| 15.30-16.00 | Pharmacist | Session too long and complicated. Reduce to a sign-posting session and how to contact them. |
| 16.00-16.30 | HD Unit Tour & Finish | A tour of the renal unit is important. Make sure patients on the dialysis machines are available to talk to (preferably with homogeneity between the dialysis patient and the education day attendee i.e. gender, age, ethnicity). The tour is somewhat detached from the HD session presented first thing. |

Table 6.0.3 Original Education Day Format

The need to reduce the timing of the remaining sessions: transplant, dietician, psychologist, social worker and the patients' association was discussed at length. A reduction to sign-posting services rather than education delivery was controversial. Specifically the dietician and psychologist raised concerns: These are summarised in Table 6.0.4 & 6.0.5 respectively.

| Summary of the dietician's concerns: |
|---|
| <ul style="list-style-type: none"> • Suggested reduction in time slot from 45 to 5 minutes. |
| <ul style="list-style-type: none"> • Dietician: Concerned that time was needed to present the basic renal diet facts to patients. |
| <ul style="list-style-type: none"> • Countered: Dietician available at every out-patient clinic and patients referred by consultant when necessary. Risk of information over-load highlighted by expert patient. |
| <ul style="list-style-type: none"> • Dietician: Staffing levels severely compromised due to under-staffing and long-term sickness. ED provides opportunity to reach a large number of patients at once. |
| <ul style="list-style-type: none"> • Counter: Patients needed one-to-one specific advice based on their results and the generic advice could be provided in the information pack at the end of the day. |

Table 6.0.4 Dietician's Concerns

The outcome agreed was: to reduce to a 5 minute sign-posting session prior to the lunch break, with the dietician available over the lunch break to answer questions and revision of the written information included in the ED pack. The PAR methodological approach of cyclical trial, in this case for 3 months, and then review, was reiterated and helped to allay concerns and facilitate a compromise. During a one-to-one meeting following meeting 3, the dietician's compromised work environment was discussed and the facilitator was able to empathise and acknowledge her departmental constraints. Understanding and validating the dietician's concerns outside of the PAR environment, meant a trusting and respectful relationship was built and the facilitator was better able to mediate within meetings. Though the sign-posting slot was not the dietitian's ideal, she was prepared to use the cyclical

approach of trialling and evaluating. Dietetic self-management offers some individuals the potential to slow their rate of renal decline with a very strict low protein diet. However, there are complex pro and cons associated with the regime and the resultant physical and psychological impacts. The potential for diet control is highlighted during the dietitian's sign-posting session, on the education day. Follow-up however is on a one-to-one basis with the dietitian in clinic due to the individual complexities affecting diet control

| Summary of psychologist's concerns: |
|--|
| <ul style="list-style-type: none"> • Suggested reduction in time slot from 45 to 5 minutes. |
| <ul style="list-style-type: none"> • Psychologist: concerned that adaptation and coping mechanisms were essential for patients in the pre-dialysis phase and therefore education about them should be included. |
| <ul style="list-style-type: none"> • Countered: Agreement that coping mechanisms are important but not all patients will be interested or need in-put and ED is not the appropriate environment. |
| <ul style="list-style-type: none"> • Psychologist & CNS had diametrically opposed views on need for coping sessions. |
| <ul style="list-style-type: none"> • Facilitator: Suggested it be incorporated as an optional extra session at the end of the day. |
| <ul style="list-style-type: none"> • Countered: Agreement that this was a reasonable compromise and allowed patients to gauge their own needs. Sign-posting session maintained for those not opting to attend. |

Table 6.0.5 Psychologist's Concerns

The outcome agreed was: a trial reduction to a 5 minute sign-posting session prior to the lunch break, psychologist available over lunch break and optional coping and relaxation class to be added at the end of the day.

The incorporation of self-efficacy enhancing approaches to education delivery was discussed. The group agreed that all the elements identified in Bandura's (1977) Self-efficacy theory were appropriate for use with the pre-dialysis patients. However, goal setting and verbal persuasion were felt to be most appropriately utilised in the one-to-one environment and not within a group setting. The collaboration identified opportunities to incorporate vicarious and mastery experience within the amended education day format. The re-modelled Education Day format is presented in Table 6.0.6

| Time | Topic | Self-Efficacy Enhancing Opportunity |
|--------------|--|--|
| 09.30-10.00 | Introduction & Kidney Function/Disease and Anaemia | |
| 10.00-10.30 | Haemodialysis | Present with HD patient (Vicarious Learning) |
| 10.30-11.00 | Peritoneal Dialysis | Present with PD patient (Vicarious Learning) |
| 11.00-11.30 | <i>Refreshment break</i> | <i>Patient available to talk to</i> (Vicarious Learning) |
| 11.30- 11.45 | Conservative Management | |
| 11.45-11.50 | Transplantation | Present with Tx patient (Vicarious Learning) |
| 11.50- 11.55 | Dietician | |
| 11.55-12.00 | Psychologist | |
| 12.05-12.10 | Pharmacist | |

| | | |
|-------------|---|---|
| 12.10-12.15 | Kidney Patients Association & Social Worker | |
| 12.15-13.15 | <i>Lunch</i> | |
| 13.15-13.45 | Tour of the HD unit | Patients available to talk to whilst dialysing (Vicarious Learning). Tour of the HD unit and renal department (Environmental Mastery Experience). |
| 13.45-14.30 | Psychologist (Optional) | Relaxation Class (Mastery Experience) |

Table 6.0.6 Re-modelled Education Day Format Version 1

Reflexive

Conflicting opinions of patients need for coping strategy education were explored and though discrepancy remained, a compromise was reached. The possibility and probability of further change, as a product of the iterative process and as discrepancies arise and are addressed, was emphasised as a positive PAR process.

Reflection

As the alteration and reduction of sessions was explored, a focus-group type of discussion developed, where individuals' views and perspectives were acknowledged. A form of connectedness resulted within the group. The common ground, of values based on patient-centred care, facilitated the yielding of time by the dietician and psychologist, allowed the inquiry to take shape actively and move forward.

Re-Modelled Education Day Implementation

The re-modelled ED was organised by the CNS, implemented immediately and employed once monthly for the following 3 months. The presence of experienced service users, at the PD and HD talks was established. A list of potential service users was identified by the PAR HCPs. The service users were approached by the HCP identifying them, the role explained and their interest in the role sought. A pool of willing individuals was generated and the CNS organised their attendance at the ED.

The service users met with the HD and PD presenters prior to attending the ED, and their involvement was explained. The diverse nature of ED attendees, and their varying degrees of knowledge and confidence, was discussed with the volunteers. The need to be honest, but not brutal, in answering questions was stressed. Reassurance was given that HCP support would be in evidence throughout their involvement and the PD and HD presenters would provide on-going support where required. The CNS made further small changes in programme order, to facilitate wider service demands upon presenters. The changes were reported back to the group by the CNS and involved only minor changes to the running order of the day.

Following the success of the individual meetings, the facilitator arranged to meet with another collaborator. Discussion revealed a degree of tension between two departments. The introduction of a new service had resulted in the redefining of departmental boundaries. A combination of the assertive establishment of the new department's responsibilities and the resultant

backlash by experienced staff, who perceived their role and skills as being undervalued, had created a hostile environment.

A lack of communication and a complete absence of collaborative patient services delivery and planning became evident. The benefits to patients of combined service planning and care delivery were discussed, but addressing service development and delivery was beyond the remit of a small PAR project. However, awareness of these tensions informed the facilitator's actions and approach to participants within the meetings. If individual views and perspectives could be established as having commonalities within the PAR, then perhaps this could extend to a departmental level.

Reflection

The positive impacts and insight gained from these individual meetings led the facilitator to meet with all collaboration members individually. The principle of building relationships with individual members, beyond the confines of the group, enabled appreciation of each individual and the context within which they worked. Individual meetings were very informal and aimed at improving honest and open communication. Fostering a more personal understanding of group members and their context, facilitated inclusivity and smoothed mediation requirements.

Reflexive

Despite being a long-standing member of renal services, the facilitator's position within renal research, for the previous 5 years, and having not worked in the pre-dialysis team, allowed her to remain impartial and reduce

any bias in her approach to collaborative discussions. The use of questioning to understand, rather than challenge, consolidated this position. The facilitator worked consciously to build trust, honesty, respect and reliability into working partnerships. These were key foundations upon which effective facilitation, mediation and negotiation of conditions could occur.

Meeting 4

This meeting provided the first opportunity to evaluate the implementation of the re-modelled ED as a group. Patient participant ML offered to facilitate the session and provided four questions on a flip chart:

- How did it go?
- What worked well?
- What needs reviewing?
- How do we move forwards?

These simple open questions gave focus to the discussion. Individuals were given the opportunity to reflect on their practice and the ED as a whole. The day had been reviewed well in patient feedback. Realistically, only limited inference can be drawn from these evaluations, as patients have no comparative experience, and have a propensity to want to please those caring for them. However, a number of issues were raised in PAR discussion and needed to be addressed.

Issue 1: The 5 minute time slot was too short and presenters were trying to cram in too much information and running over.

Learning Outcome: The collaborators were all agreed that that the Education Day had originally delivered too much information over the period of the day. Collaborative discussion, centred round redefining the aims of the education day clearly. The dilemma being, was the aim to increase patient knowledge, increase self-efficacy enhancing behaviours, or to facilitate treatment decision-making? Making an informed treatment choice is the single most important pre-dialysis decision individuals have to make. To do

this patients' need a clear understanding of the treatment options and the implications for life-style and quality of life. There was a need for a subtle, but fundamental shift in information provision. The aim was to increase understanding from knowledge about how treatment works, to information about how treatment is likely to impact the individual. Sign posting was defined as a self-efficacy enhancing process. By making individuals aware of the renal department i.e. renal dietician, putting a face to the department, identifying what they can do for patients, as well as how and when patients can access them, the foundations for pro-active behaviour are laid. However, the ability of the presenter to use verbal persuasion will further assure and encourage individuals to access services. Provision of a supporting document in the education pack reiterates and reinforces the information provided.

Review & Plan: Extend slot to 15 minutes and discussed the type of content feasible for delivery in the given time. Extra time would facilitate use of a power point presentation to focus on key factors. Dietician was working on revising the written information included in the education pack provided at the end of the day.

Issue 2: Patients seeking information during lunch break are not getting a break.

Learning Outcome: Most of the patients and their family/carers were keen to speak to the existing service users. The format of the ED, with service users available to talk to at lunchtime, was preventing some patients from getting a lunch break. For all attendees but especially, diabetics and elderly

individuals in poor health, the need to prevent information over-load, fatigue from what is an intense day and allow sufficient time to get lunch from the canteen. The benefits of vicarious learning were discussed and were deemed to be important, but did not over-ride the needs of individual attendees.

Review & Plan: The need for a protected lunch break for patients was identified. The decision was made to have a completely separate lunch break but compensate by increasing the time available within the presentations for service user questions. ML recommended the invitation letter include the suggestion of a packed lunch that could be eaten on site.

Issue 3: Poor attendance numbers at the education day.

Learning Outcome: Attendance at the Education Day may be daunting for some individuals for a number of reasons e.g. transport issues, fear, physical capacity, mental capacity, interest, work/family commitments. Provision of transport for those individuals needing an ambulance was already in place, however, this leaves a large number of individuals for whom travel and car-parking costs remain an issue. The collaboration decided that a follow-up phone call would act as a reminder to those who confirmed they would be attending and could provide reassurance for those having second thoughts. In the future delivery of the education day at weekends or evenings will be considered.

Review & Plan: Letters are already sent out to invite patients, but it was decided to add in a follow-up phone call to confirm attendance and to approach the local Kidney Patients Association for funds to reimburse patients their parking costs of £10 for the day.

Issue 4: Optional Coping Session was not incorporated at the end of the day.

Learning Outcome: The psychologist was against the reduction in time available to present at the education day and compromised because of majority agreement. With hindsight it would have been wise to discuss issues of contention further and agree the specific details of the optional Coping Session. This may have given greater insight into individual needs and departmental demands.

Review & Plan: The psychologist felt it was more appropriate to focus her limited time on setting up a group session for referred patients.

The level and diversity of analytic approaches used by the collaborative members, and the solutions achieved, helped to add depth and breadth to members' understanding of the education day delivery. Individuals' motivation to action exemplified the catalytic validity (Newton & Burgess 2008) advocated as being central to effective PAR.

During the three month implementation period for the education day, the CNS organising the session had taken the lead on amending timings to facilitate the needs of presenters and participants. With input from the facilitator, collaborative HCPs and the learning outcomes, a more workable timetable was renegotiated. It was this final version of the education day that individuals in the Pre-Dialysis Study would be reflecting on. The reviewed and amended format is presented Table 6.0.7

| Time | Topic |
|------|-------|
|------|-------|

| | |
|--------------|--|
| 09.30-10.00 | Introduction & Kidney Function/Disease, Strategies to slow Disease Progression and Anaemia |
| 10.00-10.30 | Haemodialysis |
| 10.30-11.00 | Peritoneal Dialysis |
| 11.00-11.30 | <i>Refreshment break</i> |
| 11.30- 11.45 | Conservative Management |
| 11.45-12.00 | Transplantation |
| 12.00- 12.15 | Dietician |
| 12.15-12.30 | Kidney Patients Association & Social Worker |
| 12.30-13.30 | <i>Lunch</i> |
| 13.30-13.45 | Psychologist |
| 13.45-14.00 | Pharmacist |
| 14.00-14.30 | Tour of the HD Unit |

Table 6.0.7 Re-modelled Education Day Format Version 2

With a reduction in time to deliver education verbally and peoples' limited capacity to retain information over a whole day, the importance of the information pack was discussed. With dietetics information under review, and other topics deemed to be well presented, a lack of practical information about wider service delivery was identified. The dietician offered to create a template document and circulate it electronically to the group for consideration. The development of the Renal Services Patient Directory development is summarised in Table 6.0.8

| PAR process | Activity |
|-------------|----------|
|-------------|----------|

| | |
|---------------------|---|
| Issue Identified | <ul style="list-style-type: none"> • Lack of collated renal service patient information |
| Process & Lead | <ul style="list-style-type: none"> • To produce a Renal Patient Service Directory. • Dietician to adapt template from new house officers' directory. |
| Development Plan | <ul style="list-style-type: none"> • Template to be reviewed by PAR electronically and feedback incorporated for further review and refinement. Myself to take over the lead due to dietician's workload and family illness. • Information librarian to advise on format according to hospital policy. • Senior member of each renal department to complete template for their area. • Service-wide review once completed. |
| Implementation | <ul style="list-style-type: none"> • PDF of Renal Service Patient Directory up-loaded to hospital intranet and website. • Photocopied & stapled copies included in the patient information pack. |
| Review/Observe | <ul style="list-style-type: none"> • Dietician negotiating pharmaceutical funding to print the directory professionally. |
| Reflect & Plan | <ul style="list-style-type: none"> • Printed booklet supplied to all pre-dialysis patients. • Departmental floor plan to be incorporated in re-prints following patient feedback. |
| Resulting Change | <ul style="list-style-type: none"> • Renal Service Patient Directory accessible to all patients. • CNS fully engaged with its use. • NHS Kidney Care has adopted the template for national use. |
| On-going Evaluation | <ul style="list-style-type: none"> • Annual review for accuracy of information. |
| Reflection | <ul style="list-style-type: none"> • Co-responsibility for component development would reduce individual pressure, provide a trusted sounding board for ideas and may avoid a standstill when external factors prevent development. • Provision of a completed Renal Research template gave an expectation of the information required and helped departments to complete their own page. • Dissemination of development plans may have increased interest and engagement with the PAR due to the evident delivery of service development. |

Table 6.0.8 Renal Services Patient Directory Development

Meeting 5

Again the revised education day had evaluated well by patients. Presenters felt they had adapted their presentations to fit the time slot available and the schedule ran to time. The dietetics department had revised the written education to be included in the education pack. The psychologist was planning to commence a group session for those patients struggling to adapt and cope. Both of these interventions would have occurred in the fullness of time, but became prioritised as patient needs were explored and provision of education adapted. The re-modelling of the ED, supportive environment of the PAR group and the acknowledgement of their hard work may have been a catalyst. Communication and understanding between the CNSs and dietician improved and they established a monthly review meeting.

Presenters of PD and HD felt the joint presentation with service users had really improved the sessions as patient queries were answered from a more appropriate perspective, with greater homogeneity than HCP could ever achieve and so had a greater impact. They also reported that the expert patients had expressed their satisfaction in helping others and sharing their experience. One service user presenting stated:

“It’s great to give something back. I remember how scary it was and thinking I’ll never be able to do that [PD] but here I am telling other people how easy it is”

Service User Co-Presenting on the PD Session

The re-modelled schedule provided a shorter day for patients and ensured a protected lunch-break. The CNSs had successfully gained funding from the Kidney Patients Association to reimburse patients for their parking costs. Attendance at the ED had improved and was now limited only by the room's capacity. A combination of improved communication with patients, car park funding and probably the better weather, dramatically improved numbers from: 2 in Dec 2009; 9 in Jan 2010; 17 in Feb 2010; 14 in March 2010; 14 in April 2010; 12 in May 2010; and 18 in Jun 2010.

Unsuccessful PAR Endeavour

Previously in meeting 4, the potential option of providing a relaxation CD in the patient information pack was mooted. Subsequently, a one-to-one meeting between the psychologist and facilitator took place. This was followed by the psychologist presentation in meeting 5. Despite an apparently positive initial meeting (Table 6.1.0), the presentation focused on why a relaxation CD should not be provided (Table 6.1.1). This unsuccessful development is reflected in the facilitator's reflexive and reflective diary account summaries of both meetings, and is presented to summarize the situation. Tables 6.0.9: illustrates the reflective account of the one-to-one meeting held between the facilitator and the psychologist.

| One-to-One Meeting: Reflective and reflexive diary accounts relating to the introduction of a relaxation CD intervention. |
|---|
| <ul style="list-style-type: none"> • Meeting in participant's office. • Discussion around the various types of specialist intervention available and the most appropriate circumstances for their use. • Use in diabetes education highlighted. • Overall benefits discussed. • Sourcing of the intervention discussed. Specialist intervention produced by the participant with four different programmes of varying length and style to suit personal tastes. • Intervention production is a time issue and potential options for support or funding were discussed. • Intervention supplied for review by collaboration members. • Participant to present on the use of the intervention at meeting 5. |

Table 6.0.9 Reflective/Reflexive Diary Account

Table 6.1.0: identifies the facilitator's reflective and reflexive diary accounts following the unsuccessful bid to introduce a relaxation CD intervention.

| Meeting 5 CD Presentation: Relaxation CD Use |
|--|
| <p>Initial Reaction Documented 08.09.2010</p> <ul style="list-style-type: none"> • Intervention presentation. Despite discussion in favour of the intervention's use and distribution, presented focused on why NOT to use it!? • I'm surprised and somewhat confused because previously the discussion seemed positive and ready for action. Collaboration members appeared to be equally as surprised as I was. • The against its use was well thought out: referencing research findings indicating poor up-take and use of relaxation CDs, the need to instruct individuals on their use resulting in HCP training needs and cost of producing the resource. No potential alternative intervention recommended. I wonder if this related to PAR activity or the need to focus on the development of the participant's own role. <p>Reflection 08.09.2010</p> <ul style="list-style-type: none"> • Did I misinterpret her response as positive because that's what I expected? |

- Did I not listen to cues in the conversation due to my belief, and influential others' beliefs, in the use of the relaxation CD intervention?
- Have I misinterpreted the psychologist's agenda and reasons for participating in the PAR?
Reflexive 09.09.2010
- Have I pressured the psychologist, resulting in a need to present the case against intervention use per se publicly?
- Is there a concern that credit for her work will be taken by me or the PAR group?
Moving Forward 09.09.2010
- Allow information to settle and discuss when the opportunity arises but before the next meeting, and in an informal manner.
- Maintain non-confrontational contact and work to rebuild confidence and trust in own working relationship and with the group.
- Acknowledge in meeting minutes and Meeting 6 that action research is about exploring options and dismissing those that are not appropriate.
- In future revisit ideas with individuals directly involved to gauge their opinion better.
- Accept that I may have been mistaken.

Table 6.1.0 Reflective/Reflexive Diary Excerpt

Meeting 6

Meeting 6 had to be cancelled due to temperatures of -10 degrees centigrade and the resulting travel chaos and poor staffing levels in departments. Electronic revision of the Renal Services Patient Directory continued.

Meeting 7

Prior to meeting 7, the facilitator attended the ED to review the presentations and talk to patients attending, to gauge their opinions and perspectives on the day. Meeting 7 was the final PAR meeting. With the final review of the Renal Services Patient Directory completed, a colour copy was supplied to all participants and the dietician was able to inform the group that sponsorship for printing had been secured for the next two years. The directory was also available on the hospital's website, thanks to the patient information librarian: (http://www.uhcw.nhs.uk/clientfiles/File/Renal_Directory_Sept-2011-doc.pdf). Initial feedback from the Pre-Dialysis Study participants, supplied with a copy of the directory, was positive, and this was relayed to the group.

Observe: The patient ED continues to be reviewed and the facilitator was able to feedback her experience of the day and the views expressed by patients.

Reflect: Two issues were raised: the presentation of treatment options at either end of the day felt disjointed, with the tour of the dialysis unit as the final session. The needs assessment study identified planned patient contact as having a positive impact, which is why it was incorporated into the re-modelled ED. ED attendees' comments reflect the same concerns and desire for patient contact. However, the timing of the tour resulted in limited patient contact and the perception of being 'rushed out of the door'.

Plan: With the PAR collaboration concluding, it became the responsibility of those involved in the ED to continue the cyclical review process that had been established. Six months post PAR and the ED continues to be evaluated at each session by patients. The importance of patient contact and treatment understanding indicated in patient evaluations has prompted the CNS team to investigate the creation of a dedicated treatment options space. The pre-dialysis patients would then be able to see exactly what treatment options entail and be able to talk to patients undergoing treatment. Specific patient feedback on wanting to receive treatment option information consecutively, rather than at either end of the ED, is under review. The logic of this arrangement is not in dispute, the issue lies with a need to reschedule an established outpatient clinic and the nephrologist and CNSs commitments. These changes are all the more encouraging as the CNS directly involved in the PAR left the service over five months ago, the process has become embedded within the wider team of colleagues. The PAR has had a lasting effect.

Following this final iterative group process, a review of the PAR achievements was presented, to identify all the positive changes the group had introduced. The facilitator was able to qualify these achievements with quotes from patients who had attended the ED and reviewed the directory. Participants expressed an interest in future collaborations and continued feedback from PhD findings. A number of participants expressed an interest in continuing to meet as an informal support network. Thanks were extended to the group for their work and support throughout the process.

Their ability to use this process in their everyday work was highlighted. Findings from the patient interviews reported in the next chapter have been, and continue to be, fed back to relevant departments.

Participant Action Research Facilitation Skills Development

Encouraging Participation

The frequency and duration of the PAR study and the meeting schedule was designed with potential participants in mind, to minimise potential barriers to participation. The frequency of meetings, every 3 months over an 18-month period, aimed not to overload busy HCPs, as well as providing implementation opportunities. Timing of meetings was negotiated with collaborators to facilitate maximum convenience. For patient participants the funding of travel and parking costs was negotiated. These considerations were designed to overcome potential barriers to participation and to maintain participation for the duration of the study. Senior management support for the study was sought and gained, to ensure protected time for meeting attendance. Additionally all collaborators were in senior positions and autonomous in their time management, potentially further reducing barriers to participation.

However, even with institutional commitment established, it is more difficult to gauge and address individual commitment. Ultimately, if an individual, for whatever reason, lacks interest in or a commitment to a project, the researcher can try to explore reasoning but has to accept the individual's

decision. Following the early withdrawal of one participant without explanation, the option to return at a later date was extended. Indeed they provided the input for their speciality into the Renal Services Patient Directory. Their desire not to continue to participate was acknowledged, but by maintaining communication facilitated their input in a context they found to be more appropriate. Despite the use of reflexive and reflective practice, sometimes a point is reached where no amount of introspection will provide insight into the unexpressed rationale of another's thought process.

Building Relationships

Relationships are a central foundation of PAR. The facilitator was an 'insider researcher' with an established reputation for being honest and open in working relationships, and with a patient-centred nursing approach. This proved beneficial in the development of trusting relationships so central to PAR success. As a facilitator it was critical to be completely open and clear about the researcher's and others roles' within PAR. The researcher's role as a facilitator, knowledgeable in the conduct of PAR, is tempered with a limitation to their knowledge of pre-dialysis education practice. The need for a diverse expert group to collaborate was identified.

Unambiguous indication was given that individuals had been invited to participate on the basis of their experience, expertise and knowledge of pre-dialysis education delivery. This aimed to set a foundation upon which to build individuals' confidence to participate. Throughout the PAR process individual views were sought, and opinions were fed back and incorporated

into the on-going research process. Individuals were supported in leading sections of the research, when they were the obvious choice with the ability to best achieve goals or where they expressed an interest in leading. However, this was tempered to ensure no one individual was overloaded or conversely dominated the progress.

There are many ways to show respect and appreciation for individuals participating in a project. Acknowledging their expertise is a good start, but a consistent appreciation, beyond words, can say more. Incorporating informal time into each meeting through the provision of home baked cakes allowed relationships to build by providing a common talking point. By making the effort to bake and provide cakes, which were renal friendly (low in potassium) aimed to be inclusive of all participants and show a personal gratitude to individuals for their participation. Cake themes followed the season's i.e. low potassium Christmas cake. It was a gesture that appeared to be appreciated and indeed anticipated. The first question at each meeting would be the type of cake for coffee break. This instantly broke the ice and helped to remove individuals mentally from the thoughts of the environment they had come from.

An additional part of the transition into PAR mode was to ensure that meetings were held away from the renal department, to reduce interruptions. Meeting rooms were always prepared and laid out in advance by the facilitator. Participants could be welcomed by the facilitator, see cakes set out

and be able to just sit down. Participants hopefully felt they were coming into an environment where they were cared for and cared about.

When participants were unable to attend, a non-judgemental approach was taken. Problems with attending usually related to departmental workload. Full meeting minutes were provided to all participants and electronic or one-to-one feedback sought. For those sending apologies, an informal one-to-one meeting was arranged to keep them up-to-date and engaged. With meeting dates agreed at the first meeting, there were no issues with regular non-attendance. Only one meeting was cancelled due to extreme weather conditions, and electronic feedback on developments was sought instead.

Power Sharing

With pre-dialysis educational in-put being the focus of the PAR, one immediate bonus was that the HCPs and renal service users potentially stood to benefit from the research, as well as the facilitator's PhD Thesis. A reduction in benefit inequality can be achieved when all participants stand to gain from the process. Recognition of varying knowledge expertise and the value it brings to PAR was explicit at both an individual and collaborative level. It was made clear at the first meeting that PAR could only work with collaborative input and the expertise each individual brought to the process.

The research process was demystified through visual, written and oral explanation in straightforward language. Through sharing knowledge, the facilitator aimed to share power. By developing individuals' understanding of

PAR and respecting their abilities, the facilitator was able to support individuals in taking the lead during parts of the research. Honest verbalisation of the specific skills required to facilitate parts of the research, that the facilitator lacked, allowed participants to gauge their position and aimed to promote confidence and engagement. The facilitator negotiated the level of support and input those taking the lead required. Importantly it was also viewed as a learning opportunity for the researcher, reversing the power dynamics within the collaboration.

Conclusion

Participant action research has provided a clear framework within which to review pre-dialysis education at the study site. The comprehensive methodological steps have been shown to facilitate the production of tangible results. The hands-on, action based nature was shown to have an appeal for clinicians. Through the application of this research process the PAR collaboration has created a theory based, improved pre-dialysis education programme, for which they are acknowledged and have ownership.

The rationale for limited frequency of meetings was to facilitate attendance by not being too onerous on individual workloads and to allow sufficient time to implement and review changes. On reflection, it may have inhibited the ability to build inter-departmental relationships due to the limited contact periods. More frequent meetings may have facilitated greater communication and understanding. However, the focus of the PAR was to introduce self-efficacy promoting behaviour and educational components. Improving service

communication would have been a bonus. Lack of communication was evident and would be worthy of future investigation.

For a first time PAR facilitator the collaboration provided a group within which to develop facilitation skills and affect practice, with fewer of the challenges and barriers associated with an open invitation to participate. However, dealing with the challenges the PAR has presented, and developing a confidence to rise to those challenges whilst working in partnership with a community, lays the foundation for future collaborations.

Collaboration members provided a spectrum of experience, perspectives and value interests, and these were fundamental to the development of the changes achieved. However, it is recognised that without the CNS's consistent determination, drive and position of influence to implement changes, facilitation of change would have been far less successful. The CNS's position of authority, as lead for pre-dialysis education, enabled rapid and decisive implementation of change. This highlighted that no matter how committed and effective a PAR group are in developing enquiries, without crucial key members capable of implementing them, little will come to fruition. The initial establishment and subsequent development of the PAR group is critical to change impact and influences success.

Chapter Seven:

**Service Users Pre-Dialysis
and Treatment Decision–
Making Experience Study
Findings**

Chapter Seven: Service Users Pre-Dialysis and Treatment Decision–Making Experience Study Findings

Introduction

This chapter presents the findings from the **Service Users Pre-Dialysis and Treatment Decision–Making Experience** (Pre-Dialysis Study). Findings were derived from 54 interviews conducted with 20 individuals, in Stage 4 renal failure during their pre-dialysis journey. Participants were recruited from the pre-dialysis clinic setting, to understand the commonalities and differences in the pre-dialysis journey. A grounded theory approach was adopted to explore the range of perceptions, of the influences impacting on treatment decision-making. In accordance with the principles of constructivist grounded theory (Corbin & Strauss 2008), the main thematic categories identified are drawn from participants' responses.

Participant quotations are labelled with their gender and age. Additionally, the 1st, 2nd or 3rd interview status is identified to give greater context to their progression through their pre-dialysis journey. Key issues are discussed at the end of each section. The key analytic themes identified in the data are: delivery of pre-dialysis education in the clinical setting; participants' perceptions of the value/benefit of pre-dialysis education; pre-dialysis self-efficacy behaviours; and treatment decision-making. The core category, 'influences impacting on the pre-dialysis education journey', was developed

to subsume these main emergent categories and provides a conceptual idea (Corbin & Strauss 2008, p105).

The socio-demographic and pre-dialysis characteristics of participants and interview statistics are set out in Table 7.0.0.

Socio-Demographic and Pre-Dialysis Characteristics and Interview Statistics

| | |
|--|----------------------------|
| Interview Participants | n 20 |
| Mean Age | 57yrs |
| Median | 61yrs |
| Mode | 64yrs |
| (Range) | (24yrs-80yrs) |
| Gender | |
| Male %, n | 50% n=10 |
| Female %, n | 50% n=10 |
| Ethnicity %, n | |
| White | 70% n=14 |
| Asian | 25% n=5 |
| Afro Caribbean | 5% n=1 |
| Participant status at study completion | |
| Pre-dialysis Clinic | 80%, n=16 |
| HD | 5%, n=1 |
| APD | 5% n=1 |
| PD | 5% n=1 |
| Deceased | 5% n=1 |
| Treatment Decisions at study completion | |
| HD | 50% n=10 |
| PD | 40% n=8 |
| Undecided | 10% n=2 |
| Interviews Completed | 90% n=54/60 Interviews |
| Interview Stages Completed | |
| | (Mean Duration in Minutes) |
| Interview 1 | 100% n=20 (46 Minutes) |
| Interview 2 | 90% n=18 (58 Minutes) |
| Interview 3 | 80% n=16 (61 Minutes) |

Table 7.0.0

Loss to follow up is identified in Appendix 8.

The first Section, entitled **the delivery of pre-dialysis education in the clinical setting**, presents participants perceptions about multidisciplinary roles in renal care that emerge from the data and the active elements having an impact. Secondly: **perceptions of the value/benefit of pre-dialysis education**, explores information formats, trust and the impact of education delivery as a catalyst for a shift in consciousness. The third section focuses on: **pre-dialysis self-efficacy behaviours**, present the active self-efficacy elements having an impact. Finally: **treatment decision-making**, presents the influence of emergent themes as they ultimately combine to impact upon the treatment decision-making process. Heuristic and analytic decision-making approaches are identified. Early treatment decision-making and HCPs influence are considered.

The delivery of pre-dialysis education in the clinical setting

Introduction

This section sets out the comparative data from participants' experience of pre-dialysis nephrology clinics and CNS clinics to illustrate the delivery of information to participants. Participants perceptions about multidisciplinary roles in renal care emerge from the data and the active elements having an impact here are: communication style, orientation to the participant, time usage, the patterns of patient engagement, tailoring of education delivery, clinical nurse specialist (CNS) mediation in negotiating the primary/secondary care interface.

Perceptions of health care professionals' roles

Nephrologist Clinic Experience

Nephrologists represent the first point of contact for patients referred from primary care. Once referred, patients remain with the same consultant and are seen by the same team of doctors. Some patients will see the consultant for a number of years with a slow and steady decline in renal function; others will be in the advanced stages of renal failure when referred and require imminent treatment. As a trusted source of information and a constant throughout the renal journey, nephrologists have the potential to significantly impact on participants' experience.

The interview data suggest a link between the role of time, the HCPs' communication style and the impact of information delivery. Those participants attending the nephrologists' clinic tended to cite the doctors' workload and time constraints as limiting consultation interaction. The data highlight the impact of time on the patients' perception of the consultation.

Nephrologists' workloads feature strongly in participants' overall impressions of the consultants, manifesting in expressions of the number of patients waiting, time pressures and delays in appointment times. This has implications for the patient perception of the consultation, as this recollection illustrates:

"If you see the doctor and you're late [going in to appointment] you just want a few words and get out, because there's so many patients waiting".

Interview 1, Male, Aged 75.

This typical response may say more about the pre-dialysis clinic set-up, than the HCPs involved. The overall consensus was that nephrologists are a trusted source of information:

"I want it from the horse's mouth [consultant]...a proper source of information"

Interview 1, Male, Aged 75.

However, with limited time this results in participants' recollection of doctors' treating the condition not the person:

“When I saw the doctor he told me your potassium level is too high you need to do this, this and this, that's it, bang goodbye! What does that mean? What effect is it going to have? When I asked, the doctor told me all you need to know is your potassium is high and it can affect your heart and he's waving me off. Don't ask a question that's about it”.

Interview 2, Male, Aged 75.

Participants' identify information delivery as opposed to discussion or explanation. Time may be an element of the contextual environment and compounded especially when patients are anxious waiting for their appointment, which is often delayed. Other participants highlight that it may be patients' pre-conceived ideas of how the doctor will behave, and how they as patients are expected to behave in return that influences communication and interaction:

“A lot of the time it's a one way conversation, I'll go in and he goes on and on telling me everything and I'm not asking questions. I'm unsure how to ask but once I have asked he's very forthcoming”.

Interview 1, Female, Aged 64.

Participants illustrate that information is being delivered, but fail to identify comprehension. Similarly where individuals fail to express issues it is difficult for doctors to explore them:

“At hospital you don't want to be a burden to them with things, there's so much going on you'd need a day to go through what is happening at clinic”.

Interview 2, Male, Aged 56.

The potential lack of communication and information delivery appear to be tempered with understanding the environmental constraint of time and patient numbers, as well as, patients' preconceived expectations. However, the evidence of paternalistic and autocratic patient care is palpable. One participant identified:

"The doctors care for your renal failure, nurses' care for people with renal failure".

Interview 3, Female, Aged 64.

Participants' perception of the HCPs' role within the pre-dialysis clinic is succinctly encapsulated.

Experiences of Clinical Nurse Specialist Clinics

Participants attending the CNS clinic tend to focus on effective communication elements and support for the individual. Building a trusting and supportive relationship was a recurrent theme, as patients discussed CNSs. "Listening" and "discussing" were identified time and again. The supportive and patient-centred nature of the relationship was important to patients, as the evidence highlights:

"The clinical nurses, they pick up on these things because they know you better, as an individual. And that is an important part of it".

Interview 2, Female, Aged 41.

The communication element of the consultation is expressed by another participant:

“When I saw her I just asked the question...Her approach is what can I do for you? The nurse asked what do you need to know, what are you worried about. It was very different”.

Interview 2, Male, Aged 36.

Participants reflected the gauging of patient need by the CNS. The CNSs cede power in the clinical agenda and nurse-patient relationship, the result being a patient-led consultation. Empathetic understanding is founded in the nursing approach as another identifies:

“The nurse gave me an hour of time and started on time, she appeared not to be hassled or rushed. There was good support and we worked in partnership”.

Interview 2, Female, Aged 49.

The creation of a trusting and supportive relationship portrayed, provides the cornerstone upon which to build education delivery and treatment decision-making. Participants focus on the elements of the consultation they found beneficial:

“The CNS listened to my concerns. She showed me the computer screen and explained the bloods. The CNS information was better than the Dr’s. She said just to phone if I needed her”.

Interview 2, Female, Aged 64.

Another recalls:

“The CNS is checking my bloods and is honest about the unpredictability of estimating a start date. Having spoken to the CNS I would now consider PD [previously discounted]”.

Interview 2, Female, Aged 56.

The patient-centred accounts are typical of participants' responses. The additional time afforded to explore individual needs, impacts on perceptions of communication style. The CNS appointment is framed very differently by participants, to the experience in the nephrologists' clinic:

“The CNS will tell you more. A Dr will go boom, boom, boom. The CNS will go through it; they look after the whole person. Drs' haven't got time so they focus on the kidney. The CNS picks up on things; they know you as a person that's the important part”.

Interview 2, Male, Aged 64.

The repeated differentiation between nephrologist and nursing input as participants compare and contrast, reiterates the impact of communication style, as well as time, on patient-centred care and information delivery. Time available for consultations is unlikely to change. However, there are implications for nephrologist communication styles. Clear depiction of the HCP distinct roles within the individuals' pre-dialysis journey, from the outset, may counter unfair comparison between HCP care provisions. However, for some, preconceived notions of the roles of doctors and nurses in information

giving require clarification. Confidence in the information provided by nurses was an issue for some:

“I don't know what she is able to say or what questions she can answer. I have got to wait; we will see what Wednesday brings”.

Interview 2, Male, Aged 75.

The data illustrate the benefit and importance of participants' referral to the CNS, at an early stage of the pre-dialysis journey, so they may benefit from the education provision and support the CNS's have the time and communication skills to offer.

Clinical Nurses Specialists Education Delivery Adaptation

Patients express adaptation of education delivery to suit individual need. The ability to build knowledge and understanding varies and is influenced by multiple factors:

“When I've seen the nurse in clinic she gave me information about dialysis and things already and she gave me booklets and I read some of them. I got more information from her, it was useful”

Interview 2, Female, Aged 40.

Another participant reflects on building knowledge:

“I’ll hear what the nurse specialist has to say again and take in as much as possible. I anticipate receiving more information at my next clinic appointment”.

Interview 1, Male, Aged 56.

Repetition and verbal confirmation of written information aided these patients’ knowledge accumulation. For others, education is associated with a more subtle process of information delivery:

“She wasn’t doing education, just sorting things out and finding out how I was, and updating my medication, I was on, so that she had got that. Then we looked at my blood charts and everything, and she asked if there was anything I needed to ask or whatever. I feel a lot happier talking to the nurse”.

Interview 2, Female, Aged 42.

For another patient, delivery style is the key:

“She (CNS) uses the graphs of creatinine which is more useful, seeing it in black and white”.

Interview 1, Female, Aged 41.

Diverse delivery of tailored pre-dialysis education is expressed.

Discussion of Clinical Nurse Specialist Clinic Experience

Varied formats of education delivery are illustrated that adapt to suit individual learning styles and desired level of knowledge. The repetitive nature and encouragement of questioning identified, allowed patients to fulfil their information needs in a safe and supportive environment. Importantly, this highlights the CNSs' ability to deliver education to a diverse population with a wide variety of learning styles and cognitive capacity, effectively. The pre-dialysis environment brings about other alterations to care provision for many patients and this is discussed in the following section.

Shifting Care Emphasis in the Primary/Secondary Care Interface

Once pre-dialysis care is instituted, there is a degree of consternation expressed by participants surrounding the provision of care. The data illustrate that to varying degrees, participants' GPs cede responsibility for care to the nephrologist and are reticent to amend or adjust care. Participants recount this as a failing in their GP and are sometimes at a loss to know who they should turn to:

“The GP and the pharmacy won't touch me with a bargepole”.

Interview 1, Male, Aged 32.

For others, the lack of communication between primary and secondary care is an issue for the provision of medication, especially erythropoietin (EPO), which is frequently prescribed for anaemia during the pre-dialysis period, by

the nephrologist, and supplied by the GP. Another consultant reacts to a participant's GP's advice:

“Take no notice of them; they deal with everything, a bit of this and a bit of that. Me I am the kidney specialist and that is my job. I just deal with kidneys and I know better”.

Interview 1, Male, Aged 36.

The portrayal of an ever-shifting care provision leaves some participants unsure of their traditional role and in many cases long-established care relationships dynamics change. Though some participants do indeed cite shared care, for one participant the perceived lack of shared care resulted in their manipulation of the consultation process:

“Sometimes I will go in and see the doctor and know exactly what I want and develop a strategy to get it”.

Interview 2, Male, Aged 26.

Dealing with HCPs who fail to communicate with one another, or who are inefficient, is identified as challenging, and often a frustrating situation for patients. The data would suggest that medication changes are a major cause of participants' concern:

“I've been trying to sort out my EPO but the GP and my consultant are saying different things. I went to clinic and it was sorted out, on the spot, by the CNS”

Interview 2, Female, Aged 56.

“The nurse got my consultant to write to the GP and she gave the dose needed because my supply ran out. She rang me last week and she said by the time you come back to clinic the surgery will have a new prescription from us”.

Interview 2, Female, Aged 40.

The CNSs are identified as sources of practical help as participants deal with problems arising during the pre-dialysis journey.

Discussion of Shifting Care Emphasis

These are an important issue for patients and the CNS is cited as a central point of reference in dealing with pre-dialysis problems and seeking practical advice and support. Such interventions solve practical problems that cause distress to individuals. For many, renal failure care is their first foray into an alien world of secondary healthcare and healthcare providers and it is something that takes time to understand and learn to negotiate. The data illustrate that by working in partnership with patients and empathising, CNSs' are able to adapt their professional approach effectively. These factors are further enhanced by effective problem solving on a practical level.

Discussion of the delivery of pre-dialysis education in the clinical setting

HCPs have been identified as a trusted source of information for patients and for most patients provide the main source of pre-dialysis education. Nephrologists are viewed by many patients as managing their kidney failure. Conversely, CNSs are identified as caring for and supporting the individual with kidney failure. These are important distinctions that emerge from the data.

The pre-dialysis clinic set-up provides the foundation of pre-dialysis education and treatment decision-making and gives a structure to individuals' pre-dialysis journey. The nephrologist has certain responsibilities for telling the patient what is wrong with them and what they suggest treating it with or otherwise. The main focus of CNSs' pre-dialysis care provision is to educate individuals about treatment options, so they are in a position to make an informed treatment decision. The importance and value of empathetic communication, emerging from the data, suggest a need to improve doctors' skills in this arena and their ability to engage with patients.

Current guidelines (NSF 2004, NICE 2008) suggest the patient should be educated about their condition and the treatment options by an experienced renal HCP, skilled in the delivery of education. This is open to interpretation by renal service providers and the routine referral of patients to pre-dialysis Clinical Nurse Specialists is ad-hoc. However, the themes emerging from the data suggest that there are distinct differences in the influence HCPs have on individual knowledge, and participants' understanding of treatment options.

These findings have implications for the identification of HCPs roles in pre-dialysis care delivery and development of a pre-dialysis care pathway. Explicitly identifying and defining HCPs roles at the earliest stage of pre-dialysis care, would lay a foundation for participants' expectations. However, these need to be set within a framework that supports holistic patient-centred care delivery. Development of a pre-dialysis care pathway needs to identify HCP roles; education component delivery and timing tailored to the individual, and give greater clarity to what can be an overwhelming pre-dialysis journey for some patients. Education components and the timing of their delivery are discussed more fully in the following section.

By seeing the consultant and clinical nurse specialist regularly at clinic, patient confidence in accessing their renal information needs has been shown to increase. The on-going support of knowing there is someone who knows them that they can contact if concerned or requiring advice, promotes patient self-efficacy and this is discussed later in the chapter.

Patients' perceptions of the value/benefit of pre-dialysis educational components

Introduction

This section presents the study findings regarding: information formats and trust; the impact of education delivery as a catalyst for a shift in consciousness; and the reality and shock associated with education and getting to grips with that.

The Impact of Written Information Delivered at First Referral

Written information in the form of the 'Help I've got Kidney Failure' booklet was supplied to the majority of participants by their nephrologist at their initial pre-dialysis appointment:

"Written literature was very useful to refer to and focused on the pros and cons. You realise that there are more facts that may change your decisions [treatment choice]".

Interview 1, Male, Aged 26.

This analytic response to the information provision is contrasted with the more emotional heuristic expression portrayed, and identification of different information within the same booklet:

"When I saw the pictures and stories in the help booklet, I realised this is a life-long treatment. It meant I was prepared to go back and ask questions".

Interview 1, Female, Aged 64.

Clearly, the written information was a catalyst that promoted more explicit thinking and the need for additional information. In many participants this resulted in information seeking.

Participants' overwhelming response when recalling their initial pre-dialysis clinic appointment, was that of raising awareness of hitherto unconsidered issues. The result was the instigation of further questions and so increasing

many individuals' levels of awareness about wider renal issues. One patient succinctly illustrates this point:

“Previously at the clinic the consultant had asked “do you want to ask me anything? And I said not really as I don't know what to ask”.

Interview 1, Female, Aged 64.

However, for a minority of participants the booklet was not appropriate, as these examples illustrate:

“I would rather see someone; it's harder to understand reading something”.

Interview 1, Male, Aged 69.

An Asian participant identified:

“Written information requires the son or daughter to translate into Punjabi, in Punjabi would be good”.

Interview 1, Female, Aged 70.

These participants were from ethnic minority groups, highlighting the need to offer suitable education provision from the earliest stage. This is especially important in light of the catalytic propensity found to be associated with initial information provision.

Though the Internet offers a wealth of information, for most participants in this study the trustworthiness of Internet sites and the fear of discovering too much information prevented its utilisation. One participant commented:

“The internet is a very good source of information but a bit of a mine field. I sometimes think I'll find things I don't want to know”.

Interview 2, Male, Aged 26.

Conversely, for a 40-year-old female participant the Internet is cited as her main and most trusted source of information. A lack of trust in a health care system that was seen as failing to help with her long-term chronic pain issue, compounded by the limited mobility this had conferred, had resulted in a reliance on the internet for information.

Discussion of Written Information

Findings show that written information provided the starting point for many patients pre-dialysis education journey. Response to initial information provision reflects the diversity of learning styles and varying information needs.

Many patients were in a position where they were unaware there was much they didn't know. The Help booklet starts to highlight to them the greater complexities and potential implications of their illness. The initial delivery of pre-dialysis information needs to recognise this potential state of unawareness.

The issue of trustworthiness of Internet information could to a degree be allayed by HCPs advocating recommend sites. However, fear of information is a more complex issue. The longer, slower process of building relationships

and confidence may result in an abatement of fear, as greater understanding is gained from trusted sources.

Reality of renal failure implications

The re-modelled pre-dialysis group education session was offered to patients between 6-12 months prior to their estimated dialysis commencement. It aimed to provide an understanding of basic kidney function and failure, treatment options, and introduces the range of renal services available. The sessions are run once a month from 09.30am-14.30pm and patients can bring someone with them for support. A multidisciplinary team of renal HCPs and current service users present the day.

The data illustrate the key theme in the participants' recollection of the day to be the reality of renal failure and its implications. For many individuals it was a dawning comprehension, as one insight exemplifies:

“Suddenly that kind of realisation, that it is you”.

Interview 2, Female, Aged 56.

Another patient reflects:

“Before the education day I didn’t rate the problem, hadn’t realised the effect”

Interview 2, Male, Aged 71.

The extensive information delivery and potentially overwhelming impact of the day is expressed by another individual thus:

“You tend to sit there and think well you’ll remember everything and it’s gone again. But I’ve got the information I took away”.

Interview 2, Female, Aged 56.

All the information presented on the education day is backed up with written information provided in a pack to support the day. Participants reflect that written information delivered throughout the renal journey, tended to be used as reference material and to share with others. Compounding the reality of their predicament are the current service users present during the education day. Vicarious learning provided the greatest impact on participants during the education day and participants’ reflections on this theme are explored in detail later in this chapter (page 324).

Participants reviewed the delivery of treatment options and sign-posting of renal services as appropriate and beneficial in making or consolidating their treatment decisions:

“It helped me with the PD decision...the information I’ve learned from other patients who are currently on treatment and having a personal discussion was a really positive experience”

Interview 3, Male, Aged 71.

For another participant, the vicarious learning had an impact on treatment decision-making:

“I went on the education day with my dad. They discussed dialysis and all the different types. What was most useful to me was the older

gentleman who came and did a talk. It was really useful to understand the ins and outs and every possible path you can take”.

Interview 3, Male, Aged 24.

Though the education day presents a large amount of information, participants express the desire to attend on just one occasion to get all the information. This makes sense in light of the demands upon some participants to attend multiple clinic appointments.

Understanding about the development of kidney disease and dialysis over time

Participants’ understanding of kidney disease and dialysis varies hugely between individuals and over time. Numerous facts influence understanding and these include vicarious learning, personal experience, experiential knowledge and personal characteristics. However, the pre-dialysis educational input and its timing were paramount to developing comprehension. For many participants without prior renal knowledge, a progressive understanding developed over time; typical examples for each interview time points are illustrated:

“My results are deteriorating but stable. Within 18 months I will need to start dialysis. Dialysis is for life...It requires a big change in lifestyle”.

Interview 1, Male, Aged 59.

“I realised I couldn’t have a transplant and that removed a glimmer of hope. I have discussed not dialysing and taking my chances. The CNS

said I'd have a few months, I don't know if she was trying to frighten me or it's a realistic scenario".

Interview 2, Male, Aged 71.

"It's invasive if they're putting your blood through a system to clean it to get the poison out. He's put me on Alpha-calcidol, he implied calcium was coming out of my bones".

Interview 3, Male, Aged 75.

The increasing technical knowledge and understanding expressed in these recollections illustrates the diverse educational input. However, for some participants misconceptions remain:

"The old kidney is still here, why don't they take them out if they are that bad?"

Interview 3, Male, Aged 69.

Some individuals capacity to comprehend the intricacies of kidney disease and dialysis was limited. In addition, progressive deterioration in renal function brings an increase in uraemia and a resulting deleterious effect on cognitive functioning. The implications for practice are twofold: firstly, CNS educational input needs to start prior to uraemia for maximum benefit; and secondly, decision-making needs to focus on the likely impact for individual lifestyle and functioning.

Information Needs Expressed

The data illustrates that for most participants their information need initially centred on dialysis options and treatment pros and cons. Once treatment options were discussed with the CNS and initial questions were answered, more detailed and pertinent concerns arise and the consideration of outcomes is alluded to:

“If my mum donated a kidney, is my mum going to be alright with one kidney?”

Interview 2, Male, Aged 26.

Another patient highlights:

“I’d like to see HD. I don’t know if I need someone else in the house if I was on PD?”

Interview 2, Female, Aged 56.

For many participants when discussing education needs towards the end of their pre-dialysis journey, they expressed satisfaction with their level of understanding. The data illustrates that focus shifts to practical issues:

“How does it feel the first time [HD]? What about parking, what are the dialysis times and where will it be? And always this question of when, when?”

Interview 3, Female, Aged 56.

A sense of limbo was illustrated throughout participant interviews the uncertainty is associated with starting dialysis and this affects participant information needs. For some participants very close to dialysis commencement, the desire for peer contact is sought. However for some the reality of dialysis remains a contested issue as they seek the answers they want, from alternative sources.

“I’m going to go to India and get a second opinion and see what they say”.

Interview 3, Female, Aged 40.

Discussion of participants’ perception of education components

Findings show that for most participants, though traumatic to some degree, the pre-dialysis journey prepares them for the treatment option of their choice and dialysis is planned. However, for a minority of participants who fail to be engaged in the pre-dialysis process, dialysis commencement will come as a result of urgent life saving intervention, with the associated distress and increased risk. Root cause analysis is imperative if a better understanding of why a failure to engage has occurred and is to be challenged.

Though pre-dialysis education provision was ad-hoc with individual need assessed by the CNSs, commonalities in experience of, and preference for varying formats are expressed. Information from HCPs was generally viewed as a trusted source, though there were exceptions. Written information was an initial catalyst and then a resource to share with others and review. For those participants attending the Education Day the overwhelming response

to it was that of a reality check, though it was reviewed as helpful and informative. The vicarious learning resulting from current service users presenting during the day was powerful and impacted strongly on participants' reflections. Vicarious learning impacting the renal journey is explored in the next section.

The impact of self-efficacy behaviours during the pre-dialysis education journey

Introduction

This section presents the study findings regarding the role and impact of self-efficacy behaviours during the pre-dialysis journey. The active elements having an impact are: vicarious learning, homogeneity and strongly positive role models, mastery and the need for diabetic mastery to regain diabetic glycaemic control. Additionally, participants with experience of life-threatening illness exhibited established coping mechanisms and these included goal setting.

Vicarious Learning

Participants reflect on a number of self-efficacy behaviours, and a diverse range of experiences has been illustrated. The impact of vicarious learning sets out comparative data from participants citing positive and negative vicarious learning. Positive vicarious learning can effectively increase self-efficacy levels if the observer perceives personal ability as comparable to a

successful role model (Bell 1997). However, negative vicarious learning or identifying with an unsuccessful model can have detrimental effects on self-efficacy level (Bell 1997). The role of vicarious learning is exposed, illustrating the impact of homogeneity and heterogeneity on the process.

Positive Vicarious Learning

The inclusion of current service users in the delivery of education, during the education day, was the most frequently recollected element of the day:

“I know the staff, and the nurses know about that sort of thing but its different when it’s the truth from a patient about how it’s affected them”.

Interview 3, Female, Aged 56.

Another participant identifies why service users were important:

“The patients presenting on the education day gave a more realistic impression”.

Interview 2, Male, Aged 71.

As the data illustrate, for most participants the vicarious learning was positive. These strongly positive vicarious role models had homogeneity with the target audience. However, others reflect on examples where, on the education day, too much heterogeneity was perceived by the participant, resulting in the expert patient not being a strong vicarious role model.

“The education day put me in the right frame of mind about PD; I just wish there’d been a younger person there to say how it goes”.

Interview 3, Male, Aged 32

When homogeneity was achieved with this same participant, the data illustrate a far greater positive impact:

“When I went up the other day for an appointment there was another lad up there. He said he forgot he was on dialysis now and you can tweak it, do a mixture of exchanges and the machine. I could relate to him it was realistic advice”.

Interview 3, Male, Aged 32.

There are lessons to be learned from this for the planning and delivery of peer education and support.

Seeing other patients having treatment on the day, the care environment and scale of the problem, gave patients a perspective on renal failure treatment within a supportive environment.

“It was interesting to see machines and the size of them and people talking, sleeping and getting on with it”

Interview 3, Male, Aged 71.

As the data illustrate, for some the scale of renal failure becomes apparent and to see other coping with treatment and ‘normal activities’ was reassuring. Visiting the dialysis unit and holding the education day within renal services is for many patients their first experience of the department. Many individuals

are seen in localised clinic settings and the study site hospital presents a daunting place. Negotiating a major teaching hospital for the first time raises anxiety in some participants, who express concerns relating to parking, locating departments, their physical capacity to cope with such a big place. An additional worry is not knowing what to do when they get there. The bonus of the education day is that participants are given a tour of the department's facilities. This begins to build a mastery of the renal department that can be built on by HCPs as participants return for further appointments.

Negative Vicarious Learning

The data reveal that unplanned vicarious learning was widespread, and in most cases provided a negative impact, as this participant exemplifies:

“Me friend, he been on haemodialysis for 10 years. He said if you ever have kidney problems don't go on it. It was quite painful for him... When I was in [hospital] a gentleman was having PD removed and HD started due to repeated infections, it put me off a bit. He was gone for hours [Surgery] his hand was all swollen”.

Interview 1, Male, Aged 69.

This example illustrates the strong homogeneity, created by a fellow countryman of similar age, and this had a significant impact on decision-making and in this case, negatively. Other participants identify colleagues, cousins, friends and peers respectively. The participants express varying degrees of homogeneity. However, the potential for even planned vicarious

learning, to confirm participant's unsubstantiated beliefs about treatment, are reflected by the data:

"I went into the dialysis unit and spoke to a female patient. She talked about going onto PD and didn't like it. She was me to a tee and I thought oh well that was a bit of a shock because she said everything I was thinking. It was almost as though she was reading my mind. She kept having infections like me. Living on her own and panicking and was happy when she changed to HD. I will listen to what they say [HCPs] and think about it but I won't let them talk me into it".

Interview 3, Female, Aged 64.

This quote identifies that for this individual, peer contact; with someone she could relate to, fed into and confirmed her concerns about PD. It also reveals her belief that HCPs have their own agenda. This example illustrates how individuals' perceptions of a vicarious learning can be divergent. A HCP may identify this as a negative vicarious learning, whereas for the participant it was evidently positive and reassuring. The careful selection of expert patients for the education day aims to present a positive example of the treatment options and avoid the portrayal of 'horror stories', which may cause anxiety. However, one has to question the balance between unrealistic optimism and potentially biased presentation of information, versus service users' realistic, if less palatable, reality.

Visual Vicarious Learning

Similar positive and negative vicarious learning were expressed by participants' utilising a treatment option DVD. The data illustrates that the visual vicarious learning, portrayed by the DVD subjects, engendered the same descriptive range of homogeneity versus heterogeneity of experience. The educational benefits of the DVD, participants identify as, the ability to replay sections and use the DVD as reference material. Visual vicarious learning can be shared with others and increase individuals awareness of the dialysis options and treatment demands. The sharing of a DVD may provide a much more suitable education format for family members' dependant on age and information processing. As the data illustrate:

“Being able to see the setup is more helpful...you can study it and re-run it”.

Interview 1, Female, Aged 49.

Conversely, for a number of patients the DVD failed to provide a realistic reference point. The DVD presents patients who are settled and managing well on their treatment and living so-called 'normal lives'. Patient's prior vicarious learning of treatment options or existing comorbid illnesses makes them aware of their actual or potential lack of perceived normality. This engendered distrust and dismissal of the information portrayed, as one patient suggests:

“Patients full of life and energy. It's what you want to happen but it's not realistic, well not for me anyway”.

Interview 1, Female, Aged 41.

For another participant the perceived lack of reality portrayed revealed deeper emotional concerns:

“It was like everything was normal, for most patients. I guess it’s not and that’s what you’re not being shown. Then you think are you on your own?”

Interview 2, Female, Aged 41.

Many patients are already living with complex health issues and with a restricted lifestyle. This has implications for the way in which individuals are prepared in advance of viewing the DVD. HCPs need to help individuals focus on the impact treatment is likely to have on their quality of life and lifestyle, as this has been shown to be a central decision-making consideration. Preparing participants to focus on treatment practicalities, rather than the peers themselves, may help to reduce alienation.

Experiential Vicarious Learning

For some participants renal disease was not a new issue and their articulated experience of earlier renal treatment was much more personal:

“It’s been a lifelong illness but I started to understand properly when I was about 10. I’ve been in and out of hospital all my life. I’ve had experience with the medical environment all my life”.

Interview 1, Male, Aged 24.

The participant's apparent ease with the healthcare environment expressed comes from the trust and confidence built over a lifetime of care and never knowing anything else. Conversely, recollections from a participant first requiring renal treatment as a teenager, engender very different emotions:

“As a teenager it was devastating, the end of the world. I felt my life was over. I was constantly exhausted and shattered. I was reliant on my parents which was so frustrating... My transplant and kidney problems have taken away my choice of how many children I wanted”.

Interview 1, Female, Aged 38.

The loss of lifestyle, independence and ultimately control experienced, especially at a time when peers would be gaining greater independence as teenagers, persists into adulthood, as compromised fertility remains an issue. With a failing transplant, education relating to recent developments in treatment options and establishing a trusting patient/HCP relationship, are important in helping to maintain autonomy and control.

The data illustrates, that the impact of extensive direct vicarious learning, was found to engender diametrically opposed coping and control strategies for some individuals:

“I tend to deal with everything myself. I don't think I had thought about that because I have a disease I don't want to be involved with somebody because it would involve them dealing with it. My sister's [PCKD] husband had a breakdown”.

Interview 1, Female, Aged 56

Conversely, for one participant with experience of both HD and PD, and whose transplant was failing:

“Sometimes you’re better off not knowing so you don’t sit and worry about it. I try not to dwell on it because it’s depressing. The idea of a transplant operation is much more daunting and scarier when you’ve got a child”.

Interview 2, Female, Aged 38.

These recollections simply illustrate the diverse and complex influences affecting individual approaches to pre-dialysis care and treatment decision-making.

Mastery Opportunities

This section, examines the mastery opportunities emerging from the data. Dietary advice and the commencement of EPO offered the opportunity for mastery experience as the data illustrate:

“I saw the diabetic dietician and now I’m carb counting. I feel much more positive about the future”.

Interview 2, Male, Aged 32.

Another participant explains:

“I’ve started EPO injections and was taught to self inject by the CNS”.

Interview 2, Female, Aged 56.

Mastery experience increased participants' confidence in their ability to manage their renal condition. However, when mastery is advocated, but unrealistic expectations are proposed, the result can be disempowering:

“The dietician tells us I’ve got to stop eating mangos, bananas and potatoes. It’s all to do with potism [potassium]...I seen the CNS’s and my potassium is still there”.

Interview 3, Male, Aged 69.

The potential for potassium results to continue to worsen, regardless of strict dietary concordance, was undisclosed to this individual. More immediately the participant didn’t understand the potential impact on the stability of their diabetic regime. Ultimately, the patient is disempowered. Not only do they fail to achieve safe potassium levels but in addition lose control of their once established diabetic regime. Delivery of dietetic information can result in the emphasis of control being shifted from HCPs, to the patient. Therefore, further decline in results may be viewed by the individual or others as a failing or lack of concordance, when in reality it may be unavoidable. This has implications for education delivery, where the full disclosure of potential outcomes may help preserve self-efficacy.

The data illustrate that on occasions when the information participants felt they needed had not been satisfied, individuals would resort to less trusted sources of information. The Internet was utilised out of necessity, when information provision was deemed to be lacking:

“I have looked for diet advice on the internet because there was no hospital advice. My potassium level was too high and I knew there were foods with potassium in I needed to avoid”.

Interview 2, Male, Aged 75.

Another individual explains:

“Initially I was left in the dark. The consultant gave me no information so we trawled the internet and worked out all the options [treatment options]”.

Interview 1, Female, Aged 49.

The data highlight a failure in information delivery. However, the side effect of this was mastery experience, and though driven by necessity, each participant had increased their confidence to self-manage and gained a greater degree of control of their renal situation. For one participant, virtually housebound with pain and lacking trust in HCPs, the Internet was her primary source of information:

“GPs don't know too much about the condition. The best thing is to go on the Internet. I got information from the Internet about night cramps and using quinine. Then I went to my GP because of this very severe cramp and the GP prescribed quinine. After that the cramp attacks reduced. I rely on the Internet; my motto is if you want to know, Google it”.

Interview 1, Female, Aged 40.

The GP's validation of her self-diagnosis consolidated her mastery experience and promoted confidence in continued Internet use.

Diabetes Mastery

One particular issue highlighted in the data was the increase in hypoglycaemic attacks suffered by diabetic participants:

“I had emergency admissions twice, first to the diabetic ward then ward 50 [nephrology], when me medication was altered. I had a month of hypos [hypoglycaemia] and thought I would die. I've listened to the doctors and packed up smoking, reduced my drinking and stick to the diabetic and renal advice”.

Interview 3, Male, Aged 69.

Despite concordance with HCP advice, participants can still struggle to maintain control but more importantly they begin to lose control of self-care behaviours that were once perceived to be stable. As renal function declines and adjustment to a low potassium diet is necessary, many diabetics lose staple foods utilised for glycaemic control:

“I've had hypos. I haven't had them for a long, long time, which I thought was strange. I'm doing all the right things I think”.

Interview 3, Female, Aged 79.

The problem, beyond the immediate risks associated with hypoglycaemic attacks, is the impact on participants' psychological functioning. The loss of

perceived long-established control mechanisms has a bearing on individuals' future confidence in their ability to adapt and cope with new healthcare issues. Therefore, HCPs need to forewarn individuals, of potential alteration to glycaemic control, and enable participants to rapidly regain mastery. When individuals receive advice from the dietician and follow guidance, they highlight the need for feedback on the impact of their self-management:

“I have had advised from dieticians regarding my diet and I acted upon it. But I've had no feedback following alterations to my diet and the effect of these changes”.

Interview 1, Female, Aged 72.

The data identifies that patients remain unsure as to the diet they should be having, and their ability to self-manage and master the situation is severely restricted. It would appear that the quality of dietician information provision is not in question with the patients. However, the availability and appropriate timing of information and the need for follow-up is illustrated. This has implications for participants' confidence and future self-efficacy, in adapting to and mastering new healthcare situations. For HCPs the need is to clearly and honestly portray the potential for temporary diabetes upset and provide the requisite support to help individuals rapidly regain control. Participants then benefit from forewarning; mastery of renal-diabetes is expected and as a result damage to self-efficacy may be limited. Conversely for those participants expressing a range of established coping skills associated with effective diabetes control, this offers a foundation upon which to sow the notion of transferrable skills to self-management of their renal care.

Goal Setting

Goal setting played a key role for some participants. Those participants, who express the use of established psychological coping strategies, were individuals who had experienced an extended period of life-threatening illness:

“We’ve had Christmas, then it’s my birthday, then our golden wedding anniversary, so that’s how we get on with it”.

Interview 3, Male, Aged 71.

Goal setting provided not only the psychological long term coping mechanism, as expressed here, moreover it was utilised in practical terms:

“I’m able to do things in 3 hour bursts. Now I plan rest time into my day. That way I can do what I want and don’t feel guilty when I rest because it’s planned”.

Interview 2, Female, Aged 49.

These quotes illustrate the effectiveness of goal setting for these individuals in the context of their daily lives. One must consider whether the goal setting or the life threatening illness came first and what impact they have upon each other. The use of setting simple short-term goals such as planning in rest periods to achieve other periods of activity, illustrates a particularly important coping mechanism in a cohort of patients expressing increasing lethargy over the pre-dialysis period. HCPs are ideally placed to promote the use of simple

goals that help participants to manage their desired life style and their deteriorating health context.

Discussion of the impact of self-efficacy behaviours during the pre-dialysis education journey

Vicarious learning has been identified as an important and high impact source of information, for participants' treatment option understanding. The findings demonstrate both positive and negative vicarious learning impact on individuals' decision-making. The data suggests strongly positive role models have homogeneity with the target audience. Where participants perceive too much heterogeneity it resulted in the service user not being a strong role model for the individual. There are lessons to be understood from this for the delivery of peer education and support.

For those individuals attending the Education Day the data have illustrated provision of environmental mastery that begins to build confidence in coping with the environment and mastering the dialysis routine.

The loss of perceived long established diabetic control and the resultant deleterious impact on participants' health has been illustrated. The need to forewarn participants and the subsequent need for rapid diabetic mastery, to prevent loss of self-efficacy, has been illustrated.

To understand individuals' diverse perspectives and personal contexts takes time, a trusting relationship and communication skills. The CNSs are therefore best placed to fulfil these needs.

Treatment Decision-Making Influences

Introduction

Finally, this section presents the study findings regarding the emergence of treatment decision-making and sees the influence of the identified themes ultimately combine and impact upon the process. Heuristic and analytic approaches are identified. Early treatment decision-making occurs when participants have limited renal knowledge but vicarious learning informs, influences and confirms treatment choices. HCPs influence treatment decision-making by highlighting and challenging poorly informed decisions. The philosophy of a free treatment choice is unrealistic and counterproductive for some participants. Impacting upon and influencing treatment decision-making is: personal and vicarious learning; nephrologists' paternalistic attitude; key criteria and perceived necessity.

Heuristic and analytic decision-making processes used by participants'.

The written information provided early on in the pre-dialysis journey, provides basic treatment option information. This has been identified as a catalyst, moving participants from a state of not knowing there are wider renal issues to one of raised consciousness, if not completely comprehending, that wider issues exist. Participants tended to state a treatment option preference from a very early point in their pre-dialysis journey. For some individuals the pre-dialysis phase of care is part of a much longer renal journey and one would

expect individuals to have considered potential future treatment scenarios. However, for others it is a very new experience, yet individuals make provisional treatment choices, based on very limited information, and whilst in a potential state of limited renal understanding. The data illustrate that for some participants' heuristic decision-making is employed:

“Given the choice I'd have treatment at home. I don't want to be in hospital”.

Interview 1, Male, Aged 64.

Another participant highlights:

“Going to Stratford three times a week, I don't think much of that idea. The obvious easy way to have it is done through the night at home”.

Interview 1, Female, Aged 76.

The focus on quality of life and lifestyle is clearly presented. Age and mobility also play a part in the convenience individuals assign to treatment options. Another approach to decision-making took the form of an analytic style where a risk-benefit analysis was utilised:

“There's decisions to be made and I'd like to get on with them. APD has advantages because you're more independent and can do it at night. Daytime one is much more intrusive. If you had to do HD three mornings a week it would be like a little part-time job”.

Interview 2, Male, Aged 71.

Along with the analysis of the pros and cons associated with treatment options, this individual employed coping strategies and is mentally prepared to deal with alternatives. For another individual their age played a much greater role in their analytic approach to decision-making, in spite of a rapid deterioration in their renal function and the imminent need to select a treatment option:

“I would prefer all the information up front, to get all the facts...I tried to delay as long as possible to give me time to think...I decided that I would have PD and hopefully the machine overnight...There might come a time in my life when I actually need a transplant more urgently. Important decisions, I will wait until I have got this sorted first [PD]”.

Interview 1, Male, Aged 26.

Despite being compelled to choose a treatment option, he remained cognisant of the bigger picture beyond the immediate urgency.

Another important consideration emerged from the data. Treatment equipoise and a philosophical approach to treatment based on patient choice, resulted in the presentation of treatment options as a free choice for individuals. The early written information and the DVD offered to individuals encompass the philosophy of patient choice but fails to illustrate potential treatment contraindications preventing free choice, as one patient criticises:

“It allows you to build up hopes and then you find you can’t do the one to suit your lifestyle. It gives the impression of a completely free choice and this is unrealistic”

Interview 2, Male, Aged 32.

Though these particular components do mention, that not all treatment options will be suitable for all patients, they do not explicitly state that some will be contra-indicated or why this may be the case. The pre-dialysis journey brings fluctuating emotions for most individuals, and a shift in consciousness relating to renal failure and its treatment. However, the unnecessary late delivery of treatment choice contra-indications has been shown to compound individuals' emotional fragility:

“Because of heart failure I can't have surgery again and this affects my renal treatment [PD contra-indicated]. It makes me feel very low and I can't do anything about it. I'm struggling to hide it from the family”.

Interview 2, Male, Aged 71.

Having decided on his dialysis option at an early stage, it was not made clear until some months later that the option selected would not be feasible. The resultant effect was disappointment, a lowering of mood and a change in family dynamic, with a reversal in the normal support roles. This has implications for the delivery of care. Identification of potential treatment options and contra-indications needs to occur prior to patient decision-making to avoid unnecessary upset. With some participants actively seeking information from the earliest point, and early treatment decision-making revealed, this therefore needs to be identified at first referral to pre-dialysis care.

Vicarious learning incorporated into the education day offers the opportunity for individuals to confirm their treatment decisions. However, for a few participants it is only at this point, when physically faced with the treatment options, that the reality of what treatment involves becomes clear. The involvement of family and carers in the education day is encouraged and the importance of this emerges from the data. For a husband (renal patient) and his wife (main carer) the education day's vicarious learning, provided by an older male patient on APD, evoked diametrically opposed perspectives:

“I thought it was final! I don't think I realised I've got to go on dialysis until that day. I think it brings it home a bit quicker...There was a guy there; he was demonstrating you know that whatever was wrong he had converted his garage; boom -- boom -- boom and he just made it seem so easy. It would be ideal. But she (wife) was saying you can't have that [PD]”.

Interview 2, Male, Aged 64.

The service user demonstrating APD on the day provided a strongly positive vicarious role model, with perceived homogeneity for this individual. The participant demonstrates a heuristic decision-making process based on his vicarious learning. The participant is a wheelchair bound diabetic, with a below knee amputation. His wife is his main carer, and also cares for her mother who lives with them. Her decision-making illustrates a far more analytic approach and is founded on the reality she has perceived, from the same vicarious learning:

“Then he [service user] started to explain; you have to dispose of all these bags...you have got to put the new ones in and clean the machine and he (husband) wouldn't be able to do any of that. I would have to do it all. I said to him I don't feel as if I can take any more on. And I don't mean it nastily, I think it would be too much, one step too far. Because at the end of the day I've got him and I've got my mother as well (points upstairs). I think he took it the wrong way but I said no, if he did need dialysis it would need to be done there (hospital)”.

Interview 2, (Wife of participant)

Again this challenges the notion of a free choice as the realities of comorbid disease and disability impact on capabilities. These are issues that need to be identified, from the earliest possible opportunity, so that regardless of an individual's decision-making approach, their decision is based on realistic and feasible options.

The identification of early decision-making, based on limited information and whilst participants are potentially unaware of wider implications and when very basic treatment literature is provided, has implications for the HCP delivering this information. Potential contra-indications to treatment need to be explored and identified at the earliest possible stage to avoid unnecessary deliberation or disappointment on the part of the participant. Ideally initial information delivery should allow time for exploration of individuals' initial response. With the nephrologist as the first point of contact and responsible for informing patients of their condition and treatment options, this has implications for their communication and information delivery skills. With

CNSs emerging as favoured by participants for effective and empathetic education delivery, this raises questions around the need to train doctors in these advanced communication skills. Currently, the data presented would suggest that follow-up support may be more appropriate if offered by the CNS.

The impact of HCPs on treatment decision-making

Health care professionals have been identified as a primary and trusted source of information for pre-dialysis patients. This section presents the findings concerning how HCPs impact on participants' treatment decision-making. The data has illustrated that maintenance of quality of life and lifestyle are prime concern for individuals. As the following extracts highlight, the nephrologist may not be best placed to guide treatment decision-making. Participants recalling decision-making that was guided by the nephrologist, illustrate a number of issues they encountered:

"I don't understand why the doctor would recommend PD; he has no awareness of my lifestyle. I really don't want PD".

Interview 1, Female, Aged 64.

Potentially, reasoning from a clinical perspective identified all the ideal traits in this individual for a successful PD candidate. However, failure to explore the participants' perspective yielded an inappropriate recommendation and resulted in the participant feeling alienated. Through exploration of her views and opinions the CNS was able to identify a severe and long established

body image phobia. The CNS went on to advocate for HD access creation, against medical opinion.

Other findings indicate that even when participants agreed with the treatment recommendation from their nephrologist, this could result in consternation, when it became clear that alternative treatment options had not been divulged, and honest risk-benefit analysis was not explored:

(1st Interview) “Once I was seen as an adult at the study site, transplantation was discussed seriously. I’m waiting for a transplant from my mum. If I need treatment, the PD tube at home, I’m not confident to do that. I’d start in hospital without a doubt”.

Male, Aged 24.

Following attendance at the education day the participants became fully aware of the treatment options and their implications. He had not been referred to the CNSs by the nephrologist because of his planned pre-emptive transplant.

(3rd Interview) “From seeing that fistula I thought no way. I’ll go for the tube in my tummy [PD]. HD and going in to have dialysis, with work it’s not practical. Overnight is a more practical option its convenient more than anything”.

Male, Aged 24.

The lack of referral for CNS input, late delivery of education and a failure to discuss all treatment options, resulted in this participant basing his heuristic

decision-making on prior experience. He experienced extensive care in hospital as a child and adolescent with kidney problems. Attending the education day resulted in a shift in choice from HD to PD. Though it remains to a degree a heuristic decision based on the look of a fistula. Analytic consideration of his ability to work is also expressed. However, this has implications for the consistency of education delivery. Had he gone into acute failure, prior to the education day or his transplant had failed, he would have ended up on HD on the basis of a poorly informed choice. The impact of a failure to prepare another patient on the waiting list, for a kidney/pancreas transplant, is articulated over time as reality fails to match expectation:

(1st Interview) "The consultant's gone for the best option for me. I trust he' doing the right thing for me. The average wait [for a transplant] is anywhere from 8 weeks to 18 months".

(2nd Interview) "I've got to think about it [dialysis] as the phone call hasn't come. I need to be prepared and have knowledge. It's better to have it and not use it, than go in not knowing".

(3rd Interview) "The doctor said you need to get ready for dialysis. I felt betrayed...what happened to my transplant? You said I wouldn't be on this. I felt let down".

Male, Aged 32.

These quotations underline that even with patients who are planned to have transplants, the need for education about treatment options is paramount. It is important to recognise that transplant timing is unpredictable and

transplants are not always successful and have a limited life span; hence at some point the information will be needed. Honest information giving, supported with treatment option understanding, can better prepare individuals for informed treatment decision-making and maintain trust in the patient/doctor relationship.

The need to educate participants fully about treatment options has been illustrated, as has the potential impact of ill-informed decisions. The following excerpt highlights the skill of the CNSs, in challenging participants' treatment decisions. Despite a comprehensive understanding of the treatment options, gained through the literature provided and Internet sources, this individual remained unaware of certain long-term implications:

“Before seeing the CNS I had decided to go for the one in my arm, when I just have it three days a week but at home [home haemodialysis] it seems suitable for me...The CNS said, think about it you're still young in 20 years time you could be going back through it again [dialysis] and your veins might not take it, because you've already damaged them. So you would be best using the abdomen this time around... It didn't tell me that on the website”.

The shift in consciousness impacted on treatment choice and in his approach to treatment decision-making. As his reflection illustrates:

“Your head overrules your heart...its common sense”.

Interview 2, Male, Aged 32.

His original heuristic decision, based on lifestyle factors, was replaced with an analytic process, facilitated by the CNS.

The impact of extensive vicarious learning of familial polycystic kidney disease on decision-making

The data show that extensive vicarious learning has a lasting effect on individuals and impacts heavily on their treatment decision-making.

“It’s only as I’ve got nearer and nearer to the time when I might need dialysis that I have started thinking about my mother’s experience and my sister’s experience...My mother dialysed in the 70s and my sister she had a transplant 11 years ago after being on dialysis for five years. So I saw and witnessed a lot of things, problems with the two of them...I suppose [long thoughtful pause] I tend to deal with everything myself, without wanting to involve other people only because I am not in a relationship and hadn’t been for a long time. I don’t think I had thought that because I have got the disease I don’t want to be involved with somebody, because it would involve them having to deal with it but I think in the back of my mind that might be there...I am the sort of person, and my sister is, who would rather deal with it on my own. I know how to make myself comfortable and I know how to cope...That is a very difficult thing to think about, in the future how it would affect other people”

Interview 1, Female, Aged 56.

Her extensive vicarious learning colours the participant's whole lifestyle and this is reflected in her progressive decision-making and deliberations over potential outcomes, over time:

(1st Interview) "The most important thing is being in control of your own environment and maintenance of lifestyle. Keeping things separate".

(2nd Interview) "I would now consider PD, as I can see the autonomy and control benefits".

(3rd Interview) "I'm aware of the pros and cons. I wouldn't like to have it in my own environment. I think it's just something I'd prefer [HD] and I know my sister preferred it".

Female, Aged 56.

A clear analytic approach is conveyed, however the very strong vicarious learning, based on her sisters trial-and-error wins out. This adds a heuristic element, to her decision-making, and it is difficult to say which has greater influence.

The data illustrate another participant's treatment choice. It was founded on the needs of others, as well as avoiding the treatment her mother had, and the resulting impact it would have on others.

"The consultant said, would you do home dialysis? And I said no! I ain't doing what my mum done I am not having the same as what she had... Everything was done so I could be there for my mum. And I said no it's too much, not for me, it's the effect on other people... the night-

time dialysis is a lot easier around the children and whatever...I'm making it sound a rather easier than it probably is. But it's perfect with my life. I'm here for my youngest daughter and she needs me”.

Interview 2, Female, Aged 41.

The powerful images created by both participants, of their formative years being dominated by parental dialysis demands, are translated into their consideration of potential outcomes and treatment decisions. Direct vicarious learning has a significant influence on participant decision-making and needs to be explored and recognised by HCPs as a part of the individual's decision-making process, so it can be acknowledged or challenged where necessary.

The impact of prior life-threatening illness on treatment decision-making

The data illustrate that prior life-threatening illness experience and the ability to cope with their current situation impacts on patient treatment decision-making, as the following excerpts exemplify:

“I felt completely out of control due to chemotherapy. This time I'm making the decisions so I arranged a visit to a haemodialysis unit and visited a local neighbour on peritoneal dialysis and saw how PD works and how HD works and is set up...when I saw the consultant in clinic I informed him of my choice and was prepared to argue the case...if I'd been able to see her [CNS] within a week of diagnosis it would have been really helpful. Her simple comment of being able to keep you alive for a 30 to 40 years and I thought, oh wow I was thinking 10 years

and I'm only 49...I think if I hadn't been through, what I've been through, I would have found the thought of it [dialysis] much more daunting”.

Interview 1, Female, Aged 49.

Reflection on her extensive healthcare experience, both good and bad, following a major illness had heightened the need to maintain autonomy and control. Comprehensive understanding, and an analytic decision-making process, resulted in the consideration of potential outcomes and a compromise that would bring greater lifestyle benefits:

“I would rather have a little fistula in my arm but it doesn't bring the treatment I want so I've had to weigh up the pro and cons”.

Interview 2, Female, Aged 49.

The gravity of the illness expressed, frames individual perspective and response to their renal diagnosis. Another participant articulates his established coping mechanisms.

“I had my first heart attack in 1973. All the years and what I've been through I just accept it. My heart has always over-powered my other problem”.

Interview 1, Male, Aged 71.

One can only speculate as to which came first. Did existing coping mechanisms help them survive a potentially fatal illness, or were they developed in dealing with said illness, or a combination of both? This has implications for healthcare delivery and highlights the potential for HCPs to

draw attention to individuals' established coping mechanisms and the conscious act of applying them to their renal situation. This is particularly apparent amongst the numerous diabetic participants, as this extract exemplifies:

“I’ve been diabetic for 30 years and control my diet and medication. In fact I tell the GP what I want to do”.

Interview 2, Male, Aged 75.

Participants find themselves in a whole new world of dietary, medication and lifestyle adjustments. By overtly highlighting their existing experience of adaptation, mastery, adjustment and control, through reflection on their experience, HCPs may help individuals to develop confidence, to cope with their renal predicament.

The data illustrate that for a minority of individuals, as they progress through their renal journey, questions around potential outcomes remain and about the necessity for dialysis:

“If I don’t do this [dialysis] will it kill me?”

Interview 1, Female, Aged 40.

Another participant identifies her strategy to delay treatment based on information sought from an alternative and potentially more culturally appropriate and trusted health care sources:

“I’m using diet control to prolong the pre-dialysis phase...The main thing is to halt the kidney where it is as much as possible...Abroad [India] they were saying I could delay it [treatment]”.

Interview 3, Female, Aged 40.

The initial lack of symptoms provokes questioning over the need for treatment when, to all intents and purposes, participants may feel no different. However, even at this early stage of the pre-dialysis journey, alteration in life style can delay dialysis. The failure to identify a need for dialysis, following educational input, is a cause for concern. HCPs need to challenge misconceptions and the data suggest that vicarious learning, with a strongly homogeneous role model, may be the most effective format. For some there is a persistent reticence to commit to the idea of treatment, as the following individual’s quotes illustrate:

(1st Interview) “I hate to make me mind up. I just don’t like hospitals. If it comes to it I’m dying I ain’t going there. It frightens me a machine keeping you alive; to me it’s a big pressure”.

(3rd Interview) “I don’t think I need it yet. I think why go on dialysis just to live a couple more years? It seems it will take over my life. Three times a week is a lot isn’t it. I wonder if it is worth it you see”.

Male, Aged 69.

The lack of desire for treatment was however tempered by his wife’s desperation for him to acquiesce. Through empathetic patient-centred care, the CNS was able to identify a phobia of hospitals following a traumatic

childhood incident. Compounding this was his loss of perceived diabetic control, and the participant's negative vicarious learning of a highly non-concordant HD patient, with multiple problems. This vicarious learning had a strong influence on the participant's consideration of potential outcomes. These issues coalesced into almost overwhelming negative experiential and vicarious influence. Extensive CNS input included positive vicarious learning and the mastery of diabetic control. Reassurance was provided of their right to withdraw from treatment at any time and so maintain control, which facilitated timely creation of vascular access and progression towards preparation for HD. This illustrates the importance of CNSs promoting self-efficacy enhancing behaviours in their delivery of education to pre-dialysis participants.

Service Users Pre-Dialysis and Treatment Decision-Making Experience

Study Conclusion

Patients perceived nephrologists as managing their renal disease, and they represented along with other HCPs a trusted source of information. CNSs were perceived to provide patient-centric care, with education delivery based on individual need. Their communication skills and orientation towards the participant fostered a partnership that encouraged participant engagement. CNSs acted as mediators of care within the renal environment and in re-setting of boundaries in the primary/secondary care interface. However, CNSs made limited use of self-efficacy enhancing behaviours and this has implications for future HCP training in self-efficacy theory application in clinical practice.

The delivery of education during the Education Day was based on the principles of self-efficacy theory introduced during the participant action research. This helped to develop individuals' understanding of their renal disease and the treatment options available. The identification of individuals' level of renal awareness, by HCPs, was important in the development of treatment option understanding and was needed to facilitate informed treatment decision-making. Written information was an important catalyst for a shift in consciousness, and this was compounded by the reality and shock associated with education day attendance. The education day increased individuals understanding of treatment options and helped participants to decide upon or consolidate their treatment choice.

Vicarious learning emerged as the single greatest impact on participants understanding and influenced treatment decision-making. The delivery of education by HCPs and service users, had a positive impact on attendees, and helped to guide and confirm treatment decisions. However, negative vicarious learning had an equally strong influence on individuals' treatment decision-making deliberations. Opportunities for mastery experience arose during the pre-dialysis journey but were not exploited by HCPs. However, mastery experience helped individuals to be less anxious about the renal environment and allowed some participants to take control and self-manage their erythropoietin injections. Loss of perceived glycaemic control in the diabetic participants caused anxiety and distress to participants and their family. The necessity for mastery of renal-diabetic control was identified. Individuals with extensive experience of a life threatening illness displayed established self-efficacy enhancing behaviours.

Treatment decision-making was influenced by HCPs' delivery of tailored education, facilitating vicarious learning and individuals' heuristic or analytic decision-making approach. Early treatment decision-making was identified in some participants, whilst most were poorly informed. CNSs influenced these decisions by challenging individuals' perceptions to ensure informed treatment decision-making was facilitated. The failure to identify all potential treatment options at an early stage, and explain any contra-indicated treatments, resulted in unnecessary anxiety and disempowerment of participants. Regardless of educational input and vicarious learning, for some individuals there remained key criteria that overrode all other considerations.

The grounded theory data have illustrated the components, format and delivery of education that individuals value, find effective and are beneficial in understanding kidney disease and treatment options. The importance and relevance of vicarious learning has been revealed. The influences and the impact of factors affecting individuals' self-efficacy have been illustrated. The findings demonstrate the knowledge and skills individuals seek during the pre-dialysis period.

Chapter Eight:

Discussion & Conclusion

Chapter Eight: Discussion & Conclusion

Introduction

This study has generated new insights into the importance of self-efficacy theory, informing the development and delivery of pre-dialysis education. The influence of the complex education intervention developed as part of this study; on patients' treatment decision-making has been explored. This chapter is presented in two sections: **Section One** discusses the study findings and **Section Two** explores the methodological findings. These findings are considered in relation to research evidence about intervention development and individuals' experience of pre-dialysis education and the treatment decision-making journey. The research evidence and broader policy and health care agenda are considered. Finally, the summary and conclusions of the thesis are presented.

Section One: Discussion of study findings

Delivery of pre-dialysis education in the clinical setting

This section discusses the study findings in relation to the existing literature concerning pre-dialysis education delivery in the clinical setting. Clinical Nurse Specialists (CNSs) and vicarious learning have been reported by participants as important influences on their pre-dialysis education and treatment decision-making. Engaging individuals in the learning process is central to achieving informed treatment decision-making. Pre-Dialysis CNSs have emerged as one of the key providers of patient education and are able to offer the support that individuals consider important when attending pre-dialysis clinics.

Participants have described CNSs as a constant throughout their pre-dialysis journey and support liaison with the wider renal multidisciplinary team. They have been shown to support individuals as they learn to negotiate healthcare systems and boundaries. The pivotal role of the CNS in participants' pre-dialysis journey supports the work of Zamperion et al (2009). In their comparison of nephrology nursing practice across Europe they identified:

“The advanced nurse practitioner role within nephrology has been shown to improve the efficiency of patient care, by spending quality time with patients, providing continuity of care and enhanced communication between dialysis team members” (p26)

The philosophy of patient centred care combined with extensive communication skills has shown the CNSs to be ideally placed within the

multidisciplinary team to educate patients and facilitate informed treatment decision-making. The use of multidisciplinary pre-dialysis education is advocated (Goldstein et al 2004, Inaguma et al 2006, NSF Renal Part 1 2004) and this has been shown in this study to facilitate the tailoring of education to individual need. This complements Dixon et al's (2011), quantitative exploration of the pre-dialysis journey, that found a multidisciplinary model to improve the care of individuals initiating dialysis, and reduced admissions and costs in comparison to nephrologist only care. Multidisciplinary presentation during the education day ensured expert input, but more importantly put a face to departments helping to reduce communication barriers and identified departmental remits.

The involvement of service users, in the design and delivery of patient services is a key policy driver (DoH 2000, 2004) and provides a consensus view of health-care being responsive to patient-centred needs (Ormandy 2010). The first significant outcome of the study was the re-modelled education day. This was founded on national policy driver recommendations, for patients with deteriorating kidney function:

“Referral to a multi skilled renal team, where possible at least one year before the anticipated start of dialysis treatment for appropriate clinical and psychological preparation”

(National Service Framework for Renal Services: Part-One 2004)

Furthermore, the literature review identified the potential for increased impact of education delivered by service users (Barlow 2002, Berzins et al 2009)

and the study findings support these recommendations. Indeed, study participants' strongest, and most positive recollections of the education day centre on peer contact. Firstly, peer presenters were able to describe their experience and identify real life issues to consider, and importantly they can answer attendees' questions. Selected peers, who are willing to discuss their treatment, whilst dialysing, can provide a simple and accurate description of their treatment. Peer supports focus is on the attendees asking questions pertinent to their information needs. It is not about peers delivering structured education as Lorig (1999) and Barlow (2002) describe; rather it is sharing their lived experience as Berzins et al advocate (2009).

Planned peer contact was found to consolidate individuals understanding of treatment options, identify and correct misconceptions and helped to reduce the fear and anxiety associated with the unknown. Importantly, vicarious learning identified in this study has resulted in both positive and negative impacts on the pre-dialysis journey, and this is discussed more extensively in the self-efficacy enhancing behaviours section of this chapter.

Divergent views emerge from the grounded theory about HCPs' input into participants' pre-dialysis journey. Health care professions are a trusted source of information at a time when individuals are contemplating a life-changing illness and the need for life-changing treatment. However, for most participants nephrologists were perceived to be managing their renal disease. The paternalistic and prototype exemplar approach to the patient/consultant relationship and information delivery appears to be common amongst participants' experience of nephrologists, in this study.

Participants' response to this approach was diverse and in this study ranged from frustration to contentment. It may be that the nephrologists would benefit from additional training, in promoting self-management, that prior studies have recommended (Harrington et al 2004, Roter & Larson 2002) and De Silva's (2011) review continues to advocate. There is a need to develop the advanced communication skills, that participants' so valued in CNSs delivery of education and care.

A reduction in late referrals to the nephrologist has been identified (Renal Registry 2011), due to eGFR reporting (DoH 2009). Thus it could be argued that sufficient time is available for pre-dialysis education. However, Van Biesen et al (2009), caution that early referral to the nephrologist alone may not improve outcomes. The findings of this study support this concern. For some participants an initial failure by their nephrologist to impart sufficient education, in a timely manner, became evident over time and resulted in disempowerment for the individual. The lack of perception about treatment option education, identified in this study, has reflected problems highlighted by Finklestein et al (2008), where nephrologists' failed to deliver adequate unbiased education. The role of the nephrologist within the multidisciplinary HCP team, delivering pre-dialysis education, therefore requires explicit identification to guide individuals' expectations.

With stakeholder influence upon and ownership of the changes introduced to pre-dialysis education provision, delivery has become embedded into practice and cyclical evaluation central to action research, now provides an action learning environment and this has a real and on-going impact on the

pre-dialysis environment. This has important implications for the development of renal nursing as Walker (2010) highlights:

“As yet no literature indicates what constitutes effective pre-dialysis nursing care” (page 26).

However, this study begins to identify the core characteristics participants' value in CNS education delivery and goes on to show their influence and impact in treatment decision-making. The foundations for further exploration of the CNSs role have been laid.

Participants' perceptions, of the value/benefit, of pre-dialysis education.

Varying degrees of cognitive capacity and levels of engagement with the education and treatment decision-making process have been portrayed in this study. The diverse learning styles identified add further complexity.

This study has identified that a range of educational formats are required to develop individuals' understanding of their renal disease. The CNSs need to explain the implications of renal failure in terms of continued decline, potential symptoms and this supports Ormandy's (2010) findings on treatment options. Education should include all the treatment options available; and where appropriate, include risk/benefit data as O'Connor (2007) advises. Alternative education formats need to achieve the same

standard of information provision, whilst aiming to maximise education engagement.

Early written information

This study has shown that early delivery of written information is an important catalyst for the necessary shift in individuals' level of consciousness relating to renal failure implications. For many participants the written information provided their first introduction to the potential impact of their kidney disease and the life-sustaining and life-changing treatment options available. Participant response was diverse, for some individuals with a long and slow progression to pre-dialysis it came as no surprise. However, for others it was expressed as a shocking truth. Therefore, the method of delivering this information appears important and CNSs need to provide support and reassurance to help individuals cope with what they read.

Participants in this study highlighted the need for written information that identified treatment options, treatment pros and cons, and disease progression information. Written information was reportedly used as a repeated and on-going reference source to be shared with family and carers. Written information has been identified in other studies as increasing self-care knowledge and self-care treatment selection (Mason 2008). Importantly, early education has been found to increase not only self-management options but also transplantation rates (Renal Registry 2011). The written information provided, 'Help I've got Kidney Failure', included all potential

treatment options and utilises a diverse range of presentation styles. This facilitated heuristic and analytic approaches and had appeal across the cohort as participants utilise the information suited to their learning style. The importance of early delivery of education, prior to increased cognitive impairment, associated with declining renal function, was reported. The adaptation of education to suit individual levels of cognitive capacity is crucial, if as Nulsen (2008) argues individuals are to make informed treatment decisions.

Patient information leaflets

A wider range of education formats was required to develop individuals' understanding of their renal disease. Patient information leaflets were found to support the education delivered and need to be: accurate and comprehensive; conform to patient information standards (NHS brand Guidelines 2010); include all the treatment options available; and where appropriate, include risk/benefit data as advocated by Winterbottom et al (2007). Provision of evidence based patient leaflets, in a diverse range of Asian languages, were incorporated into the resources utilised by the CNSs and continue to be used. Information provision in participants' native language was highly valued. Arguably, the incorporation of a renal treatment decision aid would as O'Connor (2007) recommends, strengthen patient information literature, the decision-making process and potentially increase decision choice satisfaction. Both NHS Kidney Care (www.nhskidneycare.org/decisionaids [Accessed Dec 2011]), and Dr Hilary

Bekker (YoDDA [accessed online Dec2011]) are currently developing and evaluating renal treatment decision-making aids/tools. As an adjunct to established self-efficacy theory based education, these have the potential to improve pre-dialysis decision quality and decision satisfaction.

Renal Services Patient Directory

Prior to being seen by the CNSs, participants identified their lack of knowledge regarding who they could or should contact if they needed renal advice. Limiting individuals' inability to be pro-active in their self-management, directly opposed the philosophy of self-efficacy theory, guiding education development. In response the PAR collaboration in consultation with other renal HCPs and renal patient charities created a Renal Services Patient Directory. NHS Kidney Care has adopted this for use in renal departments nationally. A template version with worked examples and advice to authors is available on the NHS Kidney Care: Education Datawall at www.nhskidneycare.nhs.uk/datawall/. This supports Mason's (2008) discovery that written information can increase self-care knowledge and self-care treatment selection.

DVD use and renal books

The use of a treatment options DVD, renal books written for patients and the identification of recommended or 'safe' Internet websites provided a range of formats with wider appeal. For some individuals the multilingual DVD offered

information delivery in their first language as well as visual cues. Participants reported sharing the DVD with others and it has been shown to be an appropriate format for younger family members. However, for some the lack of perceived homogeneity resulted in a failure to relate to, and subsequently engage with the information proffered. Renal books had limited appeal initially but did provide those seeking more detailed information with extensive risk/benefit reporting. The potential for books to be overwhelming in their content and information volume was evident for some individuals. However, a number of participants had extensive actual and vicarious renal experience prior to pre-dialysis referral and books provided a more appropriate level of information for them. Again it comes back to tailoring information to need (Ormandy 2010).

Internet based pre-dialysis education and patient support

This study found that most participants, regardless of computing expertise and experience, were reticent to explore the Internet, for renal sites, for fear of what they may find. The reliability of information was one concern voiced, but equally, discovering unpalatable information pertaining to their long-term condition was a substantial fear. However, the use of Internet sources out of necessity, when information provision was deemed lacking, was a reality for some.

Multidisciplinary and peer delivered education day

The involvement of service users, in the design and delivery of pre-dialysis education is in accordance with key policy drivers (DoH 2000, 2004), but more importantly it has provided a consensus view of health-care, responsive to patient-centred needs as Ormandy (2010) advocates. The Participant Action Research developed a re-modelled education day based on self-efficacy theory. The overwhelming emotional impression of the education day expressed by participants was the reality and shock associated with the education. Until faced with service users and treatment equipment, within the renal department setting, for many it had been a somewhat unreal concept, especially when the impact of CKD on their everyday health was initially very limited. Such confronting of mortality supports a major theme emerging from Morton et al's (2010) systematic review, of treatment decision-making in CKD. The review identifies:

“Some [patients] describe being startled by the conscious realisation that they could die from their disease”. (page 4)

Despite the stark reality associated with the day, the education delivered had a positive impact on patient understanding of treatment choices and for some helped to change or consolidate their treatment decisions. Yoo et al's (2011) study of self-efficacy associated with self-management supports these findings, identifying that self-efficacy enhancing interventions such as the education day, improve chronic patients self-management behaviours and their health status. Dibley (2009) too argues that self-management programmes increase patient self-efficacy in chronic disease. Furthermore,

the link between greater self-efficacy and increased selection of self-care treatment selection (Hyera et al 2011), and a delay in time to dialysis (Haakan 2010), compounds the importance of a self-efficacy theory foundation in education.

Berzins et al (2009), and Chodesh et al (2005), identify participants' self-efficacy and biomedical improvements, resulting from group delivery of education. This study has identified group education as increasing renal understanding and aiding or consolidating treatment decision-making. Interestingly, Li's (2011) study of individuals on dialysis, found educational input to impact positively on bio-psychosocial metrics in the short term. However, only psychosocial metrics remained improved at 3-month follow-up. This indicates a degree of transience in either knowledge retention or concordance. This is therefore an important consideration when developing a pre-dialysis education curriculum. Repetition during CNS clinics may be necessary.

The range of educational input has been defined but the main delivery methods recognised as valuable by participants included: peer contact, one-to-one education from the CNS, written information, and education day group delivery. Education delivery based on self-efficacy theory features strongly in participants' reflection of their pre-dialysis experience. Self-efficacy enhancing behaviours are core subjects running through the emergent themes and to avoid repartition this is discussed in its own right later in this chapter.

Participants have reported the clinical set-up to afford CNSs time with pre-dialysis individuals, and this has been shown to facilitate development of the nurse/patient relationship. CNSs were perceived as listening, discussing and supporting individuals' needs. Individuals valued a consistent and helpful point of reference. Participants reflect on a patient-centric relationship and patient-led clinic agenda. CNSs' communication techniques resulted in participants being more at ease and able to ask questions when discussing treatment options and pre-dialysis issues. CNSs, in this study, have been found to focus on patients' needs and as Ormandy (2010) highlights:

“The pivotal role of the health-care professional is to help the patient articulate and refine their information needs, then provide the relevant information to satisfy the need or gap in knowledge”. (page 99)

The pivotal role of the CNS identified in participants' pre-dialysis journey is reinforced by Zamperion et al's (2009) findings. This study has found the CNSs role to extend beyond the immediate nephrology team, to acting as mediators in the shift between the primary/secondary care providers. This is important in supporting individuals as they learn to negotiate their care needs. In this study Erythropoietin prescribing in secondary care, for provision in primary care, was found to be a particularly prevalent example of an area where individuals have difficulty and CNSs provide practical support in dealing with communication issues that arise. This is important for patients getting to grips with changing wellness levels, especially as anaemia has an all-pervading impact on energy levels and individuals' ability to cope with pre-dialysis demands.

The diverse and complex combination of educational intervention experiences expressed by participants, in response to their educational needs, indicates that they benefit most when education is tailored to meet their individual needs. The need for less systematic education regimes and more individualized approaches is advocated in Gao et al's (2011) review of established self-management programmes. This study has built on these recommendations with flexible delivery of education and this is reflected in participants' narrative. The CNSs delivery of education, tailored to individual need recognises the requisite breadth and depth of education individuals seek.

Self-efficacy behaviours during the pre-dialysis educational journey

Vicarious learning

This study has found that vicarious learning has a much greater impact on individuals' pre-dialysis journey than has previously been identified. The vicarious learning articulated by participants are diverse and profoundly influence their treatment decision-making. This had major implications for the development and delivery of pre-dialysis education and the understanding of individuals' frame of reference for the decisions they make.

On first referral to the CNS, individuals reported breadth and depth of knowledge varies widely. Participants knowledge ranges from those who are unaware of their renal condition and the implications, through to individuals

with extensive vicarious learning and a treatment decision made. Despite this variety in renal knowledge capacity, key considerations have been explicated by participants' responses, as applicable at all stages of the education process. Both positive and negative vicarious learning has been reported to be major influences on individuals' pre-dialysis considerations.

The incorporation of vicarious role models, to present alongside HCPs on the education day had a considerable impact on attendees. Participants expressed trust, reality and truth in peer delivered information and appreciated their ability to 'tell it how it is', as only those with first hand experience can do. A Cochrane Review (Foster et al 2009), of chronic disease self-management programmes presented by lay leaders, identified modest short-term improvements in health perception and confidence to manage their condition. The weaker vicarious impact findings in Foster et al's review may be associated with the generic interventions reviewed. The lay leaders may have had different long-term conditions to those attending. It could be argued that this reduces homogeneity and therefore impact. In this study the delivery of information from renal patients was central to education development and delivery.

Though the principles of self-management may be universal, this study has shown that the renal homogeneity of peer presenters resulted in an increase in the efficacious impact of the education day. Within the field of lay renal education, Van Biesen et al (2009) concur, identifying that kidney disease and dialysis education, received and acquired from peer educators, resulted in greater satisfaction than nephrologist-delivered information.

Service user involvement in the education day was vital for consolidation of treatment understanding through vicarious learning, realistic presentation of treatment options and the opportunity to talk to patients as they dialysed. This study's findings are in agreement with Ormandy (2008), who also identified that pre-dialysis individuals gain insight into treatment options and how to cope from the experience of other patients. This is supported by Morton et al (2010), who argue that peer influence helps conceptualise dialysis reality. Participants have reflected on the activities of peers, whilst dialysing, and this helped them to normalise what is a daunting prospect. This is a view supported by Hughes et al (2009) who identify it as offering hope for the future.

Vicarious learning was found to be strengthened with increased similarity between peers in terms of gender, age and lifestyle, and a desire for closer matching of established and new patients was expressed. This has implications for future developments in education delivery and peer support programme development. It may be that future education days need to be tailored to suit the cohort mix better, for example younger and working participants may gain more from peer presenters reflecting these characteristics, in line with Bandura's Self-efficacy theory (Bandura 1977).

Hughes et al (2009) explored the impact of one-off peer support and found a single, short meeting to have similar perceived gains as those achieved by participants in long-term support groups. This sustains the conclusions drawn from this study about the strength of impact peer contact produces. Furthermore, these findings have implications for those individuals who, for

whatever reason, chose not to engage in the education day. The one-to-one contact with a trained service user, with similar characteristics, could take a variety of formats including face-to-face, telephone or even e-mail communication to facilitate the needs of the individual. This would be consistent with Perry et al's (2005) findings that African Americans were more likely to complete advanced directives when discussed with an African American peer compared to a professional. Additionally this could provide a time-appropriate adjunct to satisfy patients' changing education needs throughout the pre-dialysis journey. (Perry et al 2005)

The education day provides participants and their family/carers with a wealth of information; therefore each presentation is backed up with written information presented in an education pack at the start of the day. Participants indicated that though the day is long and tiring they would rather attend once and get all the information. Audit of education day evaluation forms by the CNS team, confirms individuals felt that appropriate information had been delivered and pitched at the right level.

This study has illustrated why the inclusion of family and carers is so important in the realistic delivery of information for treatment decision-making. Hubbard et al's (2010), findings concur and reflect participants' stories:

“Carers can act as conduits for information from patient to clinician and from clinicians to patient. They can also act as facilitators during deliberations, helping patients consider whether to have treatment or not and which treatment” (p 13).

The Pre-Dialysis Study identified the discrepancies in perspective brought into focus by vicarious learning, when attendees are faced with the 'day in, day out' practicalities of treatment demands. The self-efficacy foundation and vicarious learning increased understanding of the potential impact of treatment options. The benefits of peer contact on individuals' ability to understand treatment options, is reported by Ormandy (2010) and Van Biesen (2009). Vicarious learning and peer support have been associated in other studies with increased self-care and improved health outcomes (Barlow 2002, Hughes 2009).

However, what this Pre-Dialysis Study has found and others have failed to identify is the extent of negative vicarious learning and the subsequent impact it brings to bear on participants' perceptions and treatment decision-making. Hughes et al (2009), identify the potential for a negative experience in a planned peer support programme, but offer no insight or recommendations to counteract it. However, this study found negative vicarious learning to be of equal impact to positive vicarious learning, in influencing treatment decision-making.

Negative vicarious learning began to emerge in the Needs Assessment Study and has been compounded by participants in the Pre-Dialysis Education Study. Participants express a diverse range of negative vicarious learning. For some participants the influence was all-pervading and regardless of subsequent education input remained the main point of reference for treatment decision-making. For others it provided confirmation of their negative treatment beliefs and is viewed as a positive consolidatory

experience. The result was conflict between unbiased presentation of treatment options by HCPs and the reality of the lived experience.

Interestingly, for another participant a relative's negative vicarious learning served as a warning of "how not to do it", and they were able to reverse the negatives into positive learning outcomes. This may have more to do with justifying their decision for a specific treatment but provides an important insight as to how experiences can be re-framed and has implications for how HCPs deal with individuals' prior negative learning.

Vicarious learning permeates through the renal journey and has been found to strongly influence individuals pre-dialysis experience and in particular their treatment decision-making. Provision of training for peer supports would potentially enhance the positive impact and influence. The experience peers bring to those currently encountering the pre-dialysis journey has been shown to help normalise their predicament, increase understanding and influence treatment decision-making.

Mastery experience

Mastery experience has been conveyed as helping to reduce participants' anxiety, and increased their adaptation to the demands of their new health care needs. Mastery experience was not overtly identified by participants in this study as an active element of pre-dialysis education. Though individuals reflect on mastery experiences, they fail to be framed as such by the facilitating HCPs. This raises issues around the need to train HCPs in the

delivery of self-efficacy based education to achieve optimal impact, as advocated by Sturt et al (2008).

The pre-dialysis journey offers a number of opportunities for mastery experience. One of the more frequently recalled experiences was the commencement of Erythropoietin. Most participants prescribed Erythropoietin were subsequently taught to self-inject, either by the CNSs or in the primary care setting and this was viewed as a practical necessity to avoid extra health care visits. However, HCPs failed to overtly frame the experience as mastery. They missed the opportunity to emphasise individual achievement and participants increased capacity, to adapt and have control over their long-term condition, as Bandura's (1977) self-efficacy theory advocates. The same potential could be utilised by highlighting the transference of established comorbidity self-management skills, to the renal arena. This has the potential to sow the seeds of self-efficacy enhancing behaviour, to manage their own healthcare needs and fits with the verbal persuasion and mastery elements of self-efficacy theory. EPO commencement in the renal day unit, intravenous iron administration and attendance at the education day began to develop a mastery of the renal environment.

Environmental mastery

Environmental mastery has been shown in this study to be an important element in individuals' mastery experience and this has not been identified in the literature review. Participants reflected anxiously on their ability to cope

with the scale of the clinical environment and navigate the layout. Delivery of the education day within the renal department is for some participants their first experience of the main hospital environment. Individuals had to travel to the main hospital, navigate car parking, negotiate the size of the hospital site and building, and locate the renal department. Further anxiety was expressed about expectations of how they should behave in the renal department and the day unit, which is situated on the renal ward.

Successfully negotiating hurdles has been found to provide important environmental mastery opportunities and begin to build individuals' confidence in their ability to cope with the logistics of attending the hospital. Though stressful for individuals, once successfully negotiated, this has been revealed to reduce anxiety on subsequent occasions. The importance of the unit tour therefore extends beyond the normalisation and treatment decision-making benefits.

Diabetes mastery

Diabetes control for individuals in the pre-dialysis phase of their renal journey has been reported to be problematic. The increase in hypoglycaemic attacks, resulting in urgent intervention, has been identified. A discrepancy between individuals' and HCPs' perceptions of diabetes control appears to exist. HCPs therefore need to understand the individuals' beliefs and perception of diabetes control. With dietary changes and deteriorating biochemistry results, diabetes control becomes a challenge.

Individuals need to revisit diabetes education from a renal-diabetic perspective. Care provision from a renal-diabetes CNS and/or dietician provides an holistic approach and reduces the risk of conflicting advice. This is important as conflicting advice was identified as a consistent issue in those individuals who appear to be overwhelmed by the pre-dialysis challenge. Those individuals who reported being over-whelmed were exclusively participants with diabetes. HCPs need to be realistic and honest about the potential for a temporary reduction in diabetes control. Strategies need to be discussed to reduce risk and rapidly regain control. Pre-dialysis individuals and their family/carers need to be reassured about glycaemic monitoring and especially the detection and treatment of hypoglycaemia. Dietary advice needs to identify alternative slow release carbohydrates when individuals lose established staple foods.

The influence and impact of vicarious learning on individuals' has been established and holds great potential for diabetes mastery through vicarious learning. Ideally, planned contact with trained diabetic peer supporters would provide practical 'real' advice based on experience, as well as providing a positive role model to whom individuals can relate. Increased matching of individuals' characteristics between peers would further help to increase the impact of the vicarious learning.

Though self-efficacy theory is highlighted in both the renal and broader long-term condition literature review (Barlow et al 2005b, Mason 2008, Monninkhof et al 2003, Warsi et al 2004), the specific elements working to build self-efficacy enhancing behaviour are not alluded to. This study has

clearly demonstrated the influence that independent self-efficacy enhancing elements can have during the pre-dialysis journey. Additionally, the ways in which individuals have tailored and utilised these elements is described. Though the development of pre-dialysis education was based on self-efficacy theory, much of the self-efficacy enhancing practice was incidental, as opposed to planned and overt. Goa et al (2011) identified similar issues in their review of cancer self-management programmes, as a lack of staff training can lead to a failure to cover all outcomes. Conversely training HCPs in education delivery has been shown to result in a significant improvement in haemodialysis outcome measures (Wong et al's 2009). The effectiveness of education delivery has the potential to be greatly enhanced if educators were trained in the delivery of self-efficacy theory. The adaptation and development of existing training programmes (Sturt et al 2008) for the renal HCP arena is worthy of exploration.

Verbal persuasion

Verbal persuasion provided little evidence in participants' reflections. CNSs and the wider multidisciplinary team have the potential to increase patients' self-care confidence through the use of verbal persuasion as Bandura (1977) argues. Active identification of individuals' established coping and adaptation skills, especially those already managing comorbidities, explicitly highlights the transferability of those skills to their renal condition. This begins to establish a belief by the individual in their ability to cope. Identification of these mastery skills needs to be an overt act on the part of HCPs, to raise

individuals' consciousness of their self-care capacity achievements. However, participants in this study failed to identify examples of verbal persuasion and this finding is reflected in the wider literature review findings. This again feeds into the recognition that educators need to be trained in the use of self-efficacy theory, if they are to enhance individuals' confidence in their capacity to adapt and cope with their changing healthcare needs.

Goal setting

Goal setting tended to be instigated by the participant and not an active element in education delivery and treatment decision-making. Goal setting offers the opportunity to progress education and treatment decision-making in small, feasible and achievable steps. Importantly, the few participants in this study identifying goal setting do not identify it explicitly as such. Rather they identify the satisfaction of taking action to impact positively on their own health care and gain control. Individuals also identify their reliance on effective and timely feedback from multidisciplinary HCPs to achieve this. The failure to feedback on the impact of individuals' actions has ultimately been shown to be disempowering and can result in frustration for those striving to self-care.

Some participants had prior experience of life-threatening illness. These individuals reported having strong family support networks and they exhibited established coping mechanisms and these included goal setting. Participants used goal setting as a long-term coping mechanism such as reaching family

related milestones e.g. family birthdays, Christmas and anniversaries. For others it was incorporated into their everyday life such as planning rest periods, to reduce feelings of guilt about “not doing anything”, but also as a means of facilitating periods of activity. These individuals reflected their positive adjustment and adaptation to their fluctuating wellness levels. These findings are supported by Primožic et al (2012) who identified planning and problem solving as strong predictors of independence and self-management behaviours, in individuals with diabetes. Thus the importance of self-efficacy theory for enhancing educational intervention is corroborated.

These individuals were revealed to be calm throughout the education and decision-making process. The elements of support networks and healthcare experience were common amongst the group, as was the characteristic of optimism. Individuals tended to focus on what they could do, rather than what they were no longer able to do. Though individuals’ natural characteristics are unlikely to change, the potential exists to for HCP to learn much from those individuals and actively focus on remaining capability and the use of goal setting to help individuals cope and adjust.

Treatment decision-making

Treatment choice is a complex individualised process and in this study key influences have been shown to be vicarious learning, CNSs and written information. These influences coalesce to impact on the treatment decision-making process. Participants have identified diverse approaches to treatment

decision-making. Heuristic and analytic approaches to treatment decision-making have been found as individuals' decide between treatment options. Mehrotra's (2007, 2011) follow up study identified, that HD and PD option efficacy remain in equipoise. Maintenance of lifestyle was a primary consideration for many participants. However, this study has shown that some individuals make very early treatment decisions when they are unaware of the potential implication of their decision-making. The impact of individuals not being aware of how much they don't know, is supported by Ormandy (2010) whose findings indicate:

“A person who perceives that they have sufficient knowledge to overcome a problem or make a decision will not identify an information need” (page 96)

CNSs therefore need to challenge treatment decisions that are perceived to be based on limited information. Clear identification of the unrecognised consequences of individuals' original decision-making foundations is critical. Negative vicarious learning was reported to have a considerable influence on ill informed decision-making in this study.

Both negative and positive vicarious learning influenced treatment decision-making. Morton et al's (2010), study findings support this supposition, as they intimate peer contact may have greater impact than HCPs in treatment decision-making. The potential for unplanned negative vicarious learning is not alluded to in the literature review; however in this study its bearing has been shown to be substantial.

The impact of individuals' negative vicarious learning requires exploration, in the one-to-one education environment, in order to understand the context and influences guiding decision-making. Planned vicarious learning with someone similar was found to positively impact decision-making and may provide a means of counteracting prior negative learning. Importantly, this study has identified the potential for re-framing of negative learning as a learning opportunity. This approach to tackling negative vicarious learning has the potential to be explored as a technique, in tandem with the recommended training of educators in self-efficacy theory education delivery.

HCPs have also been reported as influencing treatment decision-making. The patient centric approach of the CNSs enables them to highlight and challenge individuals' levels of awareness in treatment decision-making, to ensure participant choice is truly informed. Raising individuals' consciousness of the long-term implications of treatment decisions has been shown to amend individuals approach to treatment decision-making from heuristic to analytic. CNS can therefore influence participants' decision-making approach and facilitate informed choices.

To deliver an educational intervention based on self-efficacy theory effectively requires HCPs to understand and be able to apply the principles and practices associated with self-efficacy enhancing education. Primožic et al (2010), identified a lack of facilitator training for the delivery of self-management programmes. This study's findings concur and highlight a need to recognise the necessity of training multidisciplinary renal educators, including nephrologists, in the delivery of theory based educational

interventions. The study design, incorporating participant action research that commenced prior to the Pre-Dialysis Study, has enabled the concept of self-efficacy theory to be introduced and incorporated it into education delivery. Inclusion of HCPs involved in the delivery of the intervention facilitated discussion of self-efficacy theory use, however overt application of self-efficacy enhancing behaviours in practice was limited.

Some participants, who went through the education process and made treatment decisions, identified on-going psychological adjustment to the perceived impact and implications of their choice, only to be informed that the treatment of choice was contra-indicated. Conversely, others are informed at the earliest point about their contra-indication, when they have little if any concept of the options. For these individuals the identification of a contra-indication was found to add confusion rather than clarity, due to poor nephrologist/patient communication and a lack of explanation. The impact on individuals created increased anxiety and emotional turmoil, which were avoidable. Morton et al's (2010) systematic review contradicts these findings, identifying that nephrologist-patient communication of treatment choice occurred over an extended period of time with options discussed near to the time of dialysis commencement; this was not found to be the case in this study. However, the original study findings reported in the review (Gordon et al 2000 cited Morton 2010), are dated, and rapid development of the CNSs' role and changing dynamics, in the delivery of healthcare in the renal environment, may account for the contradictory findings.

Failure to be adequately prepared for informed treatment decision-making was reported by study participants due to; expectation of a pre-emptive transplant and the nephrologists' failure to disclose transplant options, resulting in negative impacts. The education day helped to inform and amend these individuals' options as the full implications of their treatment choice became clear. The importance of the education day cannot be overstated. Even those individuals reporting to have made an informed decision, prior to the education day, identify the consolidation and indeed revision of their decision based on peer presenter impact.

The Patient Needs Assessment and Pre-Dialysis study both identified that for some individuals key criteria over-ride and over-power all other treatment considerations. Familial experience and extensive vicarious learning were found to direct decision-making. For others, necessity was the driving force and included the need to work and family function.

Similarities and disparities in influences, impacting on understanding and treatment decision-making have been identified across the cohort. Planned vicarious learning, CNS delivery of education and education day attendance had positive influences on treatment decision-making. These educational interventions are influencing self-efficacy behaviour and have a resultant impact on; changing levels of awareness and changes in treatment decisions over time as education was delivered and vicarious learning gained.

Ormandy's (2008) systematic review identifies participants as active or passive information seekers. However, this study has shown that educational input and vicarious learning impact on information needs, and that necessity

can result in a change in individuals' information receiving/seeking behaviour. The grounded theory data has given an insight into individuals lived experience and the impact of pre-dialysis education and its timing on treatment decision-making.

The study aimed to understand the dynamics of education and treatment decision-making and the impact of individuals' cognitive status, as they experienced the pre-dialysis journey, facilitating identification of commonalities across the cohort.

Parallels can be drawn between the participants in this study and other studies. Du & Yuan (2010) in their systematic review of self-management outcomes in healthcare, identify individuals' response to challenges. Those individuals deemed to have high self-efficacy have assured capabilities and rise to challenges and this is analogous to those individuals with extensive life threatening healthcare experience. Conversely, those with low self-efficacy see challenges as threats to be avoided and these characteristics are comparable with those individuals who appeared to be struggling with the pre-dialysis journey. Ormandy (2010) concurs with the high and low self-efficacy impact on education needs and treatment decision-making. Comparable findings in a broad context systematic review, add greater insight into the future potential to tailor educational intervention, based on self-efficacy levels to facilitate individual needs.

Conceptual Model Development

This chapter has discussed the themes emerging from the Grounded Theory analysis of participant interviews. Drawing upon the interviews facilitated the development of a conceptual model. Pre-dialysis education was reported to be a dynamic process with a number of important features. The conceptual model has four elements that combine and coalesce in multifarious degrees to result in the Core Theme: 'Influences impacting the pre-dialysis journey' (Figure 8.0.0).

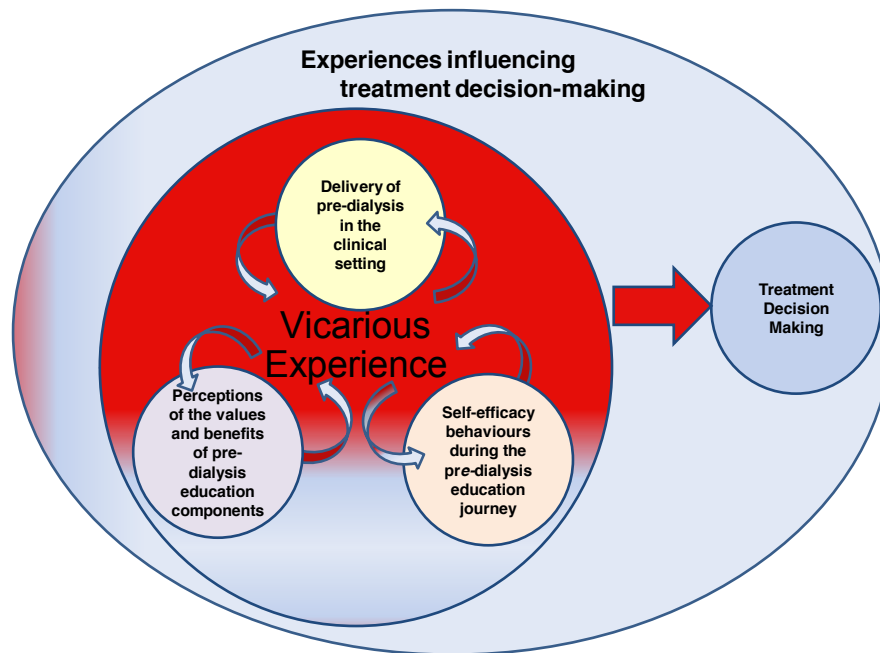
The four elements within the conceptual model are:

- Delivery of pre-dialysis education in the clinical setting.
 - Multidisciplinary team
 - Service user involvement
- Perceptions of the value and benefit of pre-dialysis education.
 - Education development
 - Education formats
 - Delivery of education
- Self-efficacy behaviours during the pre-dialysis journey.
 - Vicarious learning
 - Mastery experience
 - Goal setting and verbal persuasion
- Treatment decision-making.

- Key influences

Each of these categories forms a part of the participants' pre-dialysis story but individually they fail to capture it in its entirety. The core category 'Influences impacting on the pre-dialysis education journey' was developed to subsume these categories and is presented in the conceptual model (Corbin & Strauss 2008, p105).

Figure 8.0.0 Conceptual Model of Influences Impacting the Pre-Dialysis Journey



The starting points within this model are the delivery of pre-dialysis education within the clinical setting, participants' perceptions of the value/benefit of that pre-dialysis education, and the impact of self-efficacy behaviours upon the pre-dialysis education journey. These main themes are encapsulated to illustrate the multi-directional influence upon one another. They combine and

coalesce to influence individuals' treatment decision-making. These four themes are encapsulated within the core theme of 'Influences impacting the pre-dialysis educational journey'.

Pre-dialysis education is a complex intervention, which needs to be tailored to individual need. The link between self-efficacy theory and the impact of vicarious learning has emerged as having the greatest influence on participants' treatment decision-making. Planned vicarious learning has been identified as a beneficial influence conversely; unplanned vicarious learning was reflected upon negatively. For some individuals extensive familial experience is indelibly etched in their memory. This needs to be acknowledged by healthcare professionals and explored to challenge misconceptions. Planned vicarious learning, with someone similar, may help to redress mistaken beliefs and begin to build individuals belief in their ability to cope with their renal failure.

Extended Self-Efficacy Theory

The emphasis in Self-Efficacy Theory research to date has been focused on mastery experience, as Bandura (1977), identifies it as

“The most effective way of developing a strong sense of efficacy is through mastery experience”.

Individuals in this study have also reported the benefits of mastery experience, in building their understanding and ability to cope with their renal

failure. Indeed the research in other conditions, such as diabetes, identifies mastery as the key imperative (DESMOND 2003, Sturt 2006).

However, in the pre-dialysis cohort, where the emphasis is on treatment decision-making, so pre-treatment commencement, vicarious learning and not mastery, has emerged as having the greatest impact on service users. The extended theory developed from the study findings is:

Throughout the pre-dialysis phase of the renal patient journey vicarious learning and vicarious learning have the greatest influence and impact on treatment decision-making.

This is likely to be a temporary alteration in self-efficacy component dominance. As individuals progress on to renal replacement therapy and the mastery opportunity is expanded, then priority would be expected to revert, giving mastery experience prevalence.

Implications for the use of trained peer supporters in pre-dialysis education development and delivery are raised. Research needs to increase our understanding and utilisation of vicarious learning. The inferences that have been drawn have implications for wider healthcare research where pre-treatment education and decision-making are predominant.

Policy & Pre-Dialysis Education Curriculum

Recommendations

Policy in long-term conditions supports patient-centred services that encourage self-care (DoH 2005d). This study builds on these policies by combining these recommendations and identifying the benefit of theory-based education delivery. The importance of service user involvement in education development and delivery, have been argued. The dynamic process of education delivery and treatment decision-making requires HCPs to be trained in self-efficacy theory and the delivery of self-care education. The following curriculum identifies the timing, format and self-efficacy behaviours associated with pre-dialysis education: Table 8.0.1 Pre-Dialysis Curriculum.

Table 8.0.1 Pre-Dialysis Curriculum

| Pre-Dialysis Timeline | Pre-Dialysis Education Component | Knowledge and decision-making syllabus | Aspect of self-efficacy theory targeted by programme components |
|------------------------------|--|--|--|
| | Two day training for HCP/CNS/Nephrologists experienced in pre-dialysis education delivery | “Self-efficacy strategies to facilitate adult learning, understand intervention structure, practical skill development in support, empowering communication” (Sturt et al 2008). | Mastery Positive vicarious learning Adjustment to stress Verbal encouragement Outcome expectation |
| 12months | 1 st referral to pre-dialysis clinic nephrologist | <ul style="list-style-type: none"> • Explanation of condition and end renal failure implications. • Identification of treatment option contra-indications. Investigate if necessary. • Explanation of multidisciplinary (MDT) team members’ roles. • Provision of basic renal failure and treatment option information i.e. ‘Help’ booklet (Higgins 2012). • Peer support programme explained and offered. • Referral to a named CNS within 1m. Booked following discussion of need with the service user. | Mastery- renal knowledge Outcome expectation Mastery- knowledge of MDT Mastery- renal knowledge Vicarious learning Goal setting |
| 11months | 1 st referral to CNS with MDT available. Delivery of information based on patient need. | <ul style="list-style-type: none"> • One-to-one to identify patient information need and vicarious learning. • Potential information topics offered should include: Chronic kidney disease information, Renal replacement therapy, Physical symptoms & body image, Complications of both disease and treatment, Family & social life, Work & finance, Diet & fluid restrictions, Medication, Tests and blood results, | Vicarious learning Mastery- renal knowledge Vicarious learning, verbal encouragement, outcome expectations. Mastery- MDT team roles |

| | | | |
|---|--|---|---|
| | | <p>Psychological impact, Other patients experience, Patient organisations, Service provision (Ormandy 2008).</p> <ul style="list-style-type: none"> • Education formats include: Information leaflets, books, treatment option DVD, recommended Internet sites, trained peer support, 'Renal Service Directory'. • Referral to wider MDT based on patient identified and HCP identified need: dietitian, social worker, pharmacist, and clinical psychologist. • Peer supporter guided tour of the renal department and wider hospital facilities. • Referral to education day. • Next CNS/Renal Diabetic appointment timing arranged by mutual consent. (see adjunct session below) | <p>Vicarious learning and experience. Environmental Mastery. Goal setting</p> |
| <p><u>Diabetes Adjunct</u> Education with Renal Diabetic Specialist CNS/Dietitian/Pharmacist/Nephrologist/Peer Supporter:</p> <ul style="list-style-type: none"> • Explore individuals understanding, beliefs & perceptions of diabetes control. (Mastery capabilities) • Revisit individuals' diabetes management from a renal perspective. (Mastery achievements) • Be realistic and honest about the potential for a temporary period of readjustment in diabetes control. (Outcome expectations) • Identify strategies to reduce risk and regain control rapidly. (Mastery achievements) • Peer support to help normalise the transition period and provide real experience and coping techniques. (Vicarious learning, Verbal encouragement) | | | |
| | | | |

| | | | | |
|---------|--|--------------|--|---|
| 8months | MDT & Peer Delivered Education Day based on self-efficacy theory delivered within the renal department. <ul style="list-style-type: none"> • <i>Comfortable environment</i> • <i>Protected refreshment breaks</i> • <i>Easily accessible facilities</i> • <i>Provision of refreshments</i> • <i>Funded parking/transport</i> • <i>Evening/weekend sessions</i> • <i>Cohort specific groups i.e. young adult</i> | Time | Topic | Environmental Mastery |
| | | 09.30-10.00 | Introduction & Kidney Function/Disease, Strategies to slow disease progression and Anaemia | Mastery- renal knowledge Verbal Encouragement Outcome expectations |
| | | 10.00-10.30 | Haemodialysis & Peer | Vicarious learning & learning. Verbal encouragement & normalisation. |
| | | 10.30-11.00 | Peritoneal Dialysis & Peer | |
| | | 11.00-11.30 | <i>Refreshment break & Peer supporters</i> | Vicarious learning |
| | | 11.30- 11.45 | Conservative Management | Outcome expectation Vicarious learning & learning. Verbal encouragement & normalisation. |
| | | 11.45-12.00 | Transplantation & Peer | |
| | | 12.00- 12.15 | Dietician | Mastery- renal knowledge |
| | | 12.15-12.30 | Kidney Patients Association & Social Worker | Verbal encouragement, vicarious learning, normalisation. Vicarious learning |
| | | 12.30-13.30 | <i>Lunch</i> | |
| | | 13.30-13.45 | Psychologist | Adjustment to stress |
| | | 13.45-14.00 | Pharmacist | |
| | | 14.00-14.30 | Tour HD Unit with Peers, Peer contact | Mastery- renal knowledge Vicarious learning, |

| | | | |
|-------------|---|--|--|
| | | Audit of participants' views and opinions of the Education day for on-going cyclical evaluation and to inform continued development. | environmental mastery & normalisation |
| 11-0 months | On-going CNS/MDT clinic appointments as required. | <ul style="list-style-type: none"> Building knowledge and treatment decision-making capacity by delivering information based on patient need, as identified at 11m clinic. Treatment decision confirmed and access creation planned. | (As indicated for 11m clinic) Goal setting |
| 6months | Access | <ul style="list-style-type: none"> Access created in agreement with individuals' treatment decision and consent. Check-up of access to be completed by specific treatment option department i.e. PD or HD teams, to familiarise individuals with staff and the treatment environment and to provide vicarious learning. | Outcome expectations Mastery of access care, and environment. Vicarious learning. |
| 1-2 months | Peer orientation visit | <ul style="list-style-type: none"> Tour of department and introduction to staff and service users. Identification of usual treatment processes: where you wait, weighing yourself, useful things to bring with you, how it might feel, what the treatment process is i.e. access, observations, medications etc. On-going peer support options offered. | Mastery- renal knowledge Vicarious learning Environmental mastery Normalisation Adjustment to stress |

The pre-dialysis curriculum offers a framework for the implementation of pre-dialysis education, delivered by a multidisciplinary and peer team. The detailed description of the rationale and development of this self-efficacy based curriculum is evidenced throughout the thesis. Having achieved data saturation through exploration of the pre-dialysis journey, it has revealed the lived experience of participants and the value and benefit they ascribe to various elements contained within the curriculum. The generalisability of the study findings are greatly enhanced by the development of the conceptual model, extended self-efficacy theory and pre-dialysis curriculum. The study findings generate new avenues for exploration and these are presented in the following section.

Research Recommendations

The implications for future research development are as follows:

- Development and evaluation of a training programme for pre-dialysis educators delivering self-efficacy based education in long-term conditions.
- An Exploratory Trial of self-efficacy theory-based pre-dialysis education; delivered by HCPs and service users, trained in self-efficacy theory, to deliver the intervention; delivered in different settings and measuring decision-making quality and satisfaction.

- Identification of the self-efficacy theory-based educational intervention components that transfer to the education of emergency start renal failure individuals.
- An exploration of ethnic community perspectives on multidisciplinary and ethnic minority peer delivered pre-dialysis education impact.

An important consideration in future studies will be the incorporation of implementation theory into the research proposal. In this study, participant action research embedded practice through the process of on-going cyclical evaluation. However, it is recognised that in an exploratory or randomised controlled trial the success of implementation and sustainability may lie in the employment of implementation theory. Potentially, the PARiHS framework offers a diagnostic and evaluative tool (Kitson et al 2008, 2011), for implementing evidence into practice. However, there is also a need to increase conceptual understanding (Stirman et al 2012), and recognise the challenges involved in sustaining change (Martin et al 2012), in future studies.

Section two now explores study validity and credibility together with the strengths and limitations of the study.

Section Two: Study Validity & Credibility

This section of the chapter explores the validity and credibility of the new insights discussed in the first section of this chapter. The validity of the Participant Action Research study is explored using the Newton & Burgess (2008) action research validity framework.

The credibility of the Grounded Theory methodology is judged by the criteria specified by Charmaz (2006), as advocated by Corbin & Strauss (2008). Charmaz's criteria provide clear guidance to portraying the plausibility, presentation and analysis of the study findings.

Participant Action Research Validity

The PAR study, though strategically planned, was an organic and evolving process, and the chronological presentation of results aimed to demonstrate this. However, it is important to draw together the diverse and wide ranging examples of validity, to establish study credibility. The primary 'Outcome' and 'Catalytic' validities, and secondary 'Democratic' and 'Process' validities, identified in the Methodology Chapter (Chapter 4, p197) as defined by Newton & Burgess (2008), form the framework for collective identification of study trustworthiness.

Outcome Validity

The PAR has successfully introduced the following components to the pre-dialysis educational provision.

- Re-modelled, theory-based education day.

- Renal Services Patient Directory.
- Ethnic minority patient information leaflets.

However, though successfully implemented from a PAR methodological perspective, the components' worth is considered by the participants receiving the educational input (Chapter 7).

A final meeting to review the PAR study highlighted the progress, development and implemented changes achieved during the research. Individual feedback was invited, with a genuine request, for how to improve future PAR studies. The experience and recommendations gained from this process will be taken forward and implemented in future research and practice development.

Catalytic Validity

Catalytic validity focuses on the process whereby participants deepen their understanding and are motivated to social action. The facilitator's aim beyond that of improving education provision for pre-dialysis patients was to enable collaboration members to take responsibility in a supportive environment, to build their confidence and encourage them to make changes to practice where needed. The potential for changes to be maintained beyond the duration of the PAR study was improved because the change agents were the established senior staff members within their departments.

The cyclical processes within PAR reduced the risk associated with trialling new approaches. However, field notes identify that for both the dietician and

the psychologist this was a challenging time. Ultimately, for both it was the catalyst to change their practice and resulted in the additional provision of information for patients.

Production of the Renal Services Patient Directory maintained group-wide inclusivity. Though some individuals were particularly proactive and dynamic, open one-to-one discussions with them acknowledged the benefits of their input but also highlighted their capacity to support development of others potential. Importantly, the Education Day continues to be reviewed by patients and HCPs. The day has been renamed the 'Patient Information Day' to create a more engaging impression. Ultimately, catalytic validity delivered education changes beyond the remit of the PAR and supported outcome achievements.

Democratic Validity

Democratic validity recognizes the extent of collaboration amongst stakeholders. Democratic validity was a vital foundation upon which all other validity elements could be built. Early establishment of collaboration based democratic decision-making, from inception, allowed community knowledge to prevail. Ceding to majority opinion, showing humility and acknowledging individual and group expertise demonstrated at an early stage the facilitator's commitment to democratic collaborative decision-making. The facilitator's skills and knowledge relating to the research methodology and method, combined well with the expertise of specialist practitioners to move the PAR forward.

Throughout the study, collaboration members were encouraged and supported in taking the lead for anything from individual sessions, to the implementation of the education day. Field notes reveal that in all instances the degree of support required was identified and provided by the facilitator and/or other group members. Acknowledgement of, and drawing on, individuals' expertise, and seeking advice from an early stage, established the valuing of peoples' input.

Successful implementation of change was achieved through the iterative, multi-dimensional process that is participant action research. The ability to review major issues, such as the education day or minor issues such as individual presenters' timing within the education day, holds the key to its success. The same cyclical process is utilised but the scale and subject matter can vary. Once collaborators understand the basic principles they can apply it as they see fit.

One suggestion for future studies was the inclusion of the stakeholder community in the development of the research proposal. This was acknowledged as a just and valid recommendation that would be incorporated into future research proposals. Invitation to participate extended to the wider HCP community, was recommended to encourage engagement of those with an interest in pre-dialysis education. The current study collaborators were individually invited to participate due to their involvement with patient education delivery, or because of their extensive patient experience. Although this established an effective and well-motivated

collaboration, it is acknowledged that the breadth of stakeholder perspective may have been limited.

Process Validity

Establishment of a critical friend (CNS) and validation group (CNS, Dietician & Psychologist), created collective control in the collaboration, and facilitated alternative interpretations of findings. Findings were discussed and brought to the next meeting for consideration. Decision processes were clearly identified in the meeting minutes, meeting documents (i.e. flip charts) and reflective and reflexive diary accounts.

Despite the early withdrawal of one PAR member, the remaining collaborators stayed committed throughout the 18-month study. At times this demanded micro-facilitation on an individual basis, to resolve issues and keep momentum going. This almost invisible process of encouraging, tracking and negotiating were the threads holding the early process together. Central to development of facilitation skills was the early establishment of a critical friend in the CNS. The ability to check out thoughts and ideas in advance provided a degree of confidence in raising issues within the group.

In time a validation group developed with the dietician, CNS and psychologist, whose ability and willingness to evaluate situations critically provided a plurality of perspectives. Such diversity of consideration provided an increased confidence in outcomes when consensus was achieved. Furthermore, hand picking provides the opportunity to select charismatic

leaders; people who will go back out and influence others to change their practice. However, selectively inviting individuals to participate in the collaboration may have biased the collaborative process, through the selection of like-minded individuals. An open invitation to join the collaboration would have resulted in stronger process and democratic validity with the contribution of more diverse views.

One of the first matters addressed by the collaboration was identifying the gaps in current education delivery through process mapping as a group. The result was to process map the education day specifically to identify further issues and potential solutions. The literature review and Needs Assessment Study findings added a robust evidential basis to complement this process.

However, at times it was important to revisit the 'small changes' philosophy of PAR identified at the start. Thus, small changes could be acknowledged positively as achievements that built towards progressive improvement. Conversely, when changes were unsuccessful, the ability to review and learn from this, as part of the PAR process, was highlighted. The PAR process gave a format to start engaging individuals in critical review that acknowledged failure and allowed alternatives to be explored. Focus was regularly returned to the iterative and complementary nature of research and action. The process of identifying, planning and then actually making the change and evaluating it ready for further change, helped to take the fear of failure away, due to the on-going cyclical nature of PAR. By building in the

expectation of the PAR cycle with its continuous adaptive nature, failure could be seen as a learning opportunity rather than the final outcome.

At times during the study, challenging situations arose, and keeping a reflective and reflexive diary allowed documentation of my thoughts and feelings throughout the research process. The simple act of writing thoughts down helped to clarify issues, gave the opportunity to reflect on specific instances, and identify reflexively, interactions which may have been unintentionally influential. Most importantly, they helped to get a sense of perspective around issues. Keeping a diary was initially a forced and conscious process. As the influence of my actions became apparent through diary documentation, a positive learning cycle developed. A shift occurred from reflecting on my influence upon a situation and having to rectify it, to recognising my potential to influence a situation and avoiding it.

Grounded Theory Analysis

This second section of the chapter sets out the criteria for evaluating the Pre-dialysis Study. The specific criteria: originality, credibility, resonance and usefulness, were identified by Charmaz (2006) and are best suited to assess the value of the grounded theory. The originality of the study has been demonstrated in the first section of this chapter. The remaining criteria are now considered.

Credibility

Intimate familiarity with the topic is evidenced in the research with presentation of a multi-disciplinary literature review of self-care educational interventions in long-term conditions, and renal specific educational intervention literature. The research presents new insights into pre-dialysis education and the impact on treatment decision-making and discusses study implications that take existing literature on educational interventions into account.

The Methodology and Methods Chapters have identified: the range, number and depth of observations are sufficient to merit the claims; systematic comparison of categories; and the range of empirical settings. The Results and Discussion Chapters reveal: links between gathering of data and subsequent analysis and arguments; and the thesis provides evidence to allow an independent reader to concur with study findings.

Resonance

At the end of the data gathering no new issues regarding pre-dialysis education and treatment decision-making were being revealed. Theoretical saturation had been reached (Corbin & Strauss 2008). In addition respondent validation (Bryman 2008) ensured respondent validity. Grounded theory analysis has offered insight and made sense of individuals' lives. Taken for granted meanings about informed treatment decision-making have been

revealed and where the data indicated, links were drawn between the wider cohort and individuals' lives.

Feedback to study participants was built into the study design in the form of a six monthly newsletter (Appendix 5). Presentation of on-going study analysis to the Participants Action Research group, renal departmental meetings, a Pre-Dialysis Nursing Forum and the Kidney Education Network that includes service users, enabled other HCPs active in the pre-dialysis field to consider the implications for their practice and feedback thoughts.

Usefulness

The study of self-efficacy based pre-dialysis education has identified the impact of theoretical foundations and educational curriculum components. Furthermore it has explored the influences' impacting on treatment decision-making, as it applies to pre-dialysis individuals' everyday context. Evidence from the study will be used to provide information to patient forums, renal healthcare professionals, wider HCP groups dealing with long-term conditions, and academics.

Vicarious learning plays a central but often unrecognised role, in the lives of those experiencing the pre-dialysis journey. Future substantive research originating from the analysis is identified in the Chapter 8 Research Recommendations (p 424). The contribution this research makes to existing knowledge is described in the Results and Discussion & Conclusion Chapters.

Study Strengths

Insider researcher

The insider status of the researcher was a particular strength of the PAR. As a long-established and senior member of staff, the facilitator had credibility with the participants and this helped to increase commitment to the study. Extensive experience of renal healthcare provision led to an understanding of the issues and context. However, lack of direct involvement in the delivery or care of pre-dialysis individuals was beneficial as it bought a fresh perspective to the issue and reduced framing assumptions associated with insider research (Tichin & Binnie 1999). Use of reflective and reflexive practice from PAR inception facilitated critical engagement and challenging of barriers. The researcher had a vested authority within the service and this helped to counteract the potentially negative impact of the study's association with attainment of a higher degree, and garnered support for the PAR from the senior nursing and clinical management team.

Patient & Public Involvement Stakeholder Group

The involvement of service users was a fundamental aspect of the PAR and central to its success. The change intervention was achieved through the collaboration of a widely diverse stakeholder group inquiry. From the start of the study the researcher clearly identified participants as collaborators and co-researchers. Individuals' diverse renal expertise was acknowledged and

these coalesced to develop a robust and holistic foundation for pre-dialysis education development. Individual expertise facilitated the integration of wide-ranging knowledge and experience. The PAR produced what Waterman et al (2001), identify as involvement over a period of time.

This definition understates the wider potential impact of PAR and the fundamental elements that in this study made it so effective. Firstly, participants stood to benefit from involvement in the PAR, through improved education delivery and education provision. The PAR created a successful partnership between participants in research to affect action and change. Bridging the theory-practice gap had a direct impact on practice.

Secondly, the PAR collaboration established a robust, self-efficacy theory-based education day intervention. This has been shown to be effective in the delivery of education and informing treatment decision-making. Direct involvement in the PAR process from inception gave participants ownership of the changes. Thirdly, stimulation of participants encouraged them to be self-critical and review their practice and take practice forward. Personal development resulting from the experience of sharing and challenging ideas and developing knowledge during the PAR was empowering.

Finally, PAR participants influenced the research agenda through direct involvement in the iterative process and this was consequently emancipatory. These important impacts of PAR were achieved partly through the overarching democratic research practice that aimed to ensure inclusivity. However, findings from the literature review and Needs Assessment Study linked the existing body of knowledge on self-efficacy theory to the education

intervention development and extended participants understanding. Theoretical insight helped to interpret and explain reflections and facilitated discussion and action.

A pool of willing service users has been developed by the researcher to consult on future research proposals and service development ideas. In addition a newly established renal patient forum provides the opportunity to discuss education provision ideas with service users. However, it is acknowledged that pre-dialysis patient representation is limited and attendees may not be typical of the wider cohort.

Established self-efficacy theory education day embedded in practice

The CNS team have adopted the reflective approach established during the PAR to continued education development. User feedback continues to be sought from each education day attendee. Identification of participants education needs continues to adapt and enhance education delivery. Since the studies completion the CNSs have gone on to design a proposal to establish a permanent treatment options room.

The practical and 'hands on' nature of action learning has an appeal for nurses in clinical practice. Waterman et al (2001) identify:

“The philosophical underpinnings of nursing that emphasis holism and caring have parallels with those aspects of action research that focus

on the complexity of peoples situations and the desire to enhance peoples circumstances” (p 56)

It could be argued that expertise, as identified in this study, is viewed as a resource fundamental to the success of the changes in practice.

Triangulation

Triangulation is much debated as a concept in qualitative research. The Participant Action Research Study, garnered multidisciplinary services providers and service users’ perspectives, to develop the educational intervention. The following definitions support the holistic approach that the methodologies in this study design have coalesced to produce. Fenech-Adami (2005) discusses triangulation in terms of research completeness as its purpose, arguing that:

“It offers the possibility of discovering a holistic view of the phenomenon under study” (p 20).

Halcomb (2005) concurs arguing that triangulation:

“It provides a completeness of understanding of the concept under investigation” (p 73).

The Pre-Dialysis Study explored service users’ experience of the education provision. Analysis sought emergent-grounded theory themes. This study has employed various observers with multiple perspectives and several sources

of data and methodologies (Denzin & Lincoln 1970) in order to achieve triangulation.

Holistic View with study design, multiple analysis and multiple lenses

The Needs Assessment Study provided a retrospective reflection of participants' experience of pre-dialysis education provision. Factors influencing decision-making began to emerge. Throughout the studies data was viewed through multiple lenses to clearly identify the impact of theory, pre-dialysis education and the influences impacting on treatment decision-making. The multiple methodologies employed provided a plurality of perspectives for each of these lenses. This developed an increasing breadth and depth of understanding and knowledge. The emergent holistic picture was of a dynamic and complex pre-dialysis journey.

Study Limitations

This section reflects on the process of conducting the studies and the lessons learned, namely the study limitations, these include: limitations of the literature review; timing of the studies; MRC complex intervention framework utilisation and ethical issues raised by the study.

Limitations of the Literature Review

The purpose of conducting a literature review was twofold: i) to inform the development of a complex educational intervention in the PAR Study and ii) to guide the exploration of issues in the Pre-Dialysis Study.

Proponents of systematic reviews argue that they are more likely to generate a comprehensive and unbiased representation of the literature (Bryman 2008). Traditionally based on quantitative evidence, it could be argued that systematic reviews falter when specific variables cannot be defined in the research questions. Qualitative study methodology does not fit with traditional systematic review criteria (Bryman 2008). In seeking to understand how and why phenomena of interest are important, not simply if they work or not; qualitative data have much to contribute. This is particularly evident in complex intervention studies. Sturt et al (2006) and Mulhauser et al (2002), argue there is a need to incorporate complex intervention research into systematic reviews. The growing use of the MRC's Complex Intervention Framework has provided a format for the development of qualitative

research. However, empirical evidence from conducting the literature review suggests that the framework is not widely applied by qualitative researchers.

The inclusion of qualitative methodologies in reviews is argued to be time consuming, as qualitative abstracts provide insufficient data to determine methodological rigour (Bryman 2008), or fit with the review aims. It could be argued that the process of conducting a literature review across a broad range of potentially meaningful allied healthcare fields increases the review sensitivity and the exchange of interdisciplinary knowledge.

Conducting a systematic review of pre-dialysis education would have been a legitimate exercise and would have highlighted the lack of review data. Though not really a true limitation, in terms of usefulness it would have produced severely limited results that provided little insight into the potential impact of theory, education format and the delivery of self-management education in long-term conditions. In contrast the comprehensive search strategy guiding the literature review established the existing knowledge, and by virtue of the same process, highlighted gaps in the data. The literature review ensured the research topics were designed to explore deficits, as well as confirm or otherwise, current evidence. By incorporating review literature originating from other long-term conditions, the experience and mistakes of disciplines with more established research programmes, such as self-management education in diabetes and arthritis, could be considered in terms of theoretical and methodological approaches.

The literature review offered the benefit of being an on-going component of the study. As Corbin & Strauss (2008) highlight initial interview questions,

such as those in the Needs Assessment Study, can be formulated based on the concepts derived from the review. As themes emerge the review of pertinent data, such as decision-making, in this study was facilitated. A cut-off point for the literature review informing development of the PAR and Pre-Dialysis Studies was set. This facilitated completion of the review and satisfied the requirements of a University PhD up-grade panel. Regular updating of the review highlighted new research of relevance, that continued to inform development and are explored in the Discussion & Conclusion Chapter.

One final consideration is the conscious act of using the literature to support emergent themes and not allowing the literature to guide the emergence of themes (Corbin & Strauss 2008). The original premise for the literature review proffered by Glaser & Strauss (1967) identifies:

“Use of material bearing on the area” (p169)

This can be viewed as encouragement to consider the breadth of data available.

Timing of the Studies

From a pragmatic work-load perspective, it would have been ideal to complete the PAR study prior to commencement of the Pre-Dialysis Study recruitment. However in a time-constrained PhD study this was not feasible. Additionally, one of the PAR study strengths was its longevity and the associated benefits of successful outcomes and embedded practice (Titchen

& Binnie 1999). These would have been jeopardised if the project had been shorter. Also, feedback from the participants' baseline interviews instigated the development of the Renal Services Patient Directory, which is now incorporated into standard pre-dialysis practice at the study site.

It could be argued that a pre and post-intervention test design would have been facilitated by sequential rather than an overlapping study design. However, the Pre-Dialysis Study sought to understand the pre-dialysis educational experience and influences impacting on participants. The identification of shock and reality associated with education delivery may induce a response shift (Osborne 2006). In essence the education may enlighten participants to the fact that actually 'things aren't as bad as they thought they were' (a positive response shift) or 'things are much worse than they thought they were' (a negative response shift), negating the validity of pre and post testing.

MRC Complex Intervention Framework

Bigger questions should be raised about the guiding influence of the Complex Intervention Framework (MRC 2008) on overall study design. The Needs Assessment Study was conducted to complement the literature review and fill the research gaps identified. This aimed to provide a comprehensive and robust 'Theory Phase' foundation to this complex intervention. With hindsight, having completed the studies, the validity of the needs assessment

findings may be questioned and even the necessity for conducting it interrogated.

Firstly, the validity of certain elements of the Needs Assessment Study is explored. The study sought retrospective opinions of the types of information individuals had found useful but also components they may have utilised had they been available. Having completed the Pre-Dialysis Study, findings failed to reflect the reality of engagement with education components. In the Needs Assessment Study the potential use of DVDs and Internet sources of renal information were keenly accepted. However, the Pre-Dialysis Study identified a wide spread reticence to engage with or relate to these education components. One must therefore question whether retrospective opinions are influenced by the process of commencing and being maintained on dialysis and the resultant validity of responses.

Second the necessity for the Needs Assessment Study could be questioned. Potentially, the study could have followed the literature review, with findings informing the development of the Participant Action Research, with a potential for time and financial saving. However, the scope of the thesis was only able to address the first two phases of the MRC framework. It has helped to develop a very detailed and layered understanding of the interaction between the kinds of education inputs service users need and how they make treatment decisions and how to intervene to help them make good decisions. The Complex Intervention Framework has provided guidance and helped thinking about the different arms of future study and

outcome measures. This is discussed more fully in the research recommendations (page 396).

Ethical Issues Raised in the Study

The emotional wellbeing of the participants and the researcher conducting an investigation into potentially sensitive topics potentially has ethical implications (Bloor et al 2007). These are considered for the participant and the researcher respectively.

Participant Ethical Issues

On occasions participants became distressed during an interview. It was the researcher's responsibility to be prepared to respond to this. In one instance the interviewee was tearful in response to the interview subject matter. The individual declined the offer to stop the interview but displayed signs of anxiety. In response, the researcher gently reflected the interviewee's answers and used clarification summaries, to check understanding and allow the interviewee to guide the direction and pace of the interview. Following interview completion, the role of the renal psychologist was explained and the opportunity to discuss issues further suggested. The participant declined and identified that they felt better for "getting it off their chest". The researcher and psychologist's contact details were provided for future reference.

Researcher Ethics

The most frequent issue of concern for the researcher was the differentiation between her researcher identity and her prior renal nurse roles. Participants frequently sought clarification on renal issues. Prior to study commencement the researcher had considered the likelihood of this scenario and decided that: questions would be acknowledged, and where appropriate, answers would be deferred to the end of the interview. This would reduce any disruption and potential influence upon the interview detail. The researcher considered it important that participants felt the interview to be a two-way process, of give and take.

On one occasion a participant expressed a view based on a misconception, which could have had a significant impact on their health. In this instance, common sense as well as the NMC Code (2008) overrode any other precedence and the misconception was corrected. A more challenging and less clear-cut incident related to a diabetic patient, who was struggling to adapt her diet and as a result had virtually stopped eating. The need for dietetic input was evident, but the offer of referral was declined, so too was permission to inform her CNS of the problems she was experiencing. The potential consequences of poor nutrition intake were discussed and alternative options identified. The participant did concede to the researcher sending some diet information and this was sourced from the dietician, whilst maintaining patient confidentiality. The information was posted through the participant's door the same day. The participant had made an informed choice and the situation was deemed not so seriously threatening that it

warranted a breach of trust and confidentiality. Her biochemistry results and progress were checked on a weekly basis by the researcher, had the biochemistry results caused concern my responsibilities as a nurse would have overridden my responsibilities as a researcher and all participants knew that I was a renal nurse at the point of consenting.

The research methodologies have been discussed and their credibility and validity explored. The strengths and weaknesses of the studies and their conduct have been examined. The chapter now brings together the thesis conclusion

Thesis Conclusion

In conclusion this study has provided clarification of the influences impacting upon educational input and treatment decision-making for those individuals' experiencing the pre-dialysis journey. The rationale for this study arose from a dearth of research in the area of theory-based pre-dialysis education. This study adds to the field of research in several ways: theoretically founded development and delivery of pre-dialysis education; insight into the impact and influence of vicarious learning; and a time sequential modification of the primary self-efficacy element, active in the pre-treatment decision-making period.

The conceptual model, theory development and findings in this study extend current understanding of pre-dialysis education and treatment decision-making in the following ways. Firstly, the findings support the content and structural recommendations for education delivery (Aujoulet 2007, Berzins 2009, Iles-Smith 2005, Singh 2005). Furthermore, this study also identifies the involvement of family in the education process (Lenz et al 2005). Barlow's (2002) and Berzin's (2009) highlight the effectiveness of lay educator delivery which was also identified in this study. The need to train educators in the delivery of theory based education concurs with Goa et al's (2011) reports of a lack of facilitator training and this is compounded by Wong et al's (2009) finding that educator training improves service user outcomes. The need for clinicians to be trained in delivery of self-care education is advocated by De Silva's (2011) comprehensive review of self-management in long-term conditions.

However, in contrast to previous research, this study extends the breadth and depth of conceptual understanding of theory based pre-dialysis education. The influential impact of vicarious learning has emerged from individuals' narrative and in conjunction with other findings informs the conceptual model and development of theory. This study reveals the prevalence and significance of unplanned negative vicarious learning, which has previously not been recognised in the literature. In contrast previous studies have emphasised only the positive impact that planned vicarious learning bestows (Iles-Smith 2005, Lenz 2005).

The conceptual model (Figure 8.0.0) and new theory emerging from the findings extend and develop conceptual understanding in two main ways. Firstly, self-efficacy theory has been shown to be an effective foundation for the development and delivery of pre-dialysis education. This study has extended understanding in this area through the detailed description of the participant action research approach, employed to develop a pre-dialysis education curriculum. This addresses Barlow's (2002), systematic review criticism of studies failure to identify components. Such explicit description facilitates replication and further validation then becomes possible (Bradley et al 1999). Furthermore, functional definition is discussed and explored through the grounded theory study, facilitating the adaptation of interventions to differing contextual situations. As Hawe et al (2004), argue this is of particular importance in a patient population that is diverse, in terms of ethnicity, culture, and demographics. The few literature review studies that identify both theory foundation and education content fail to identify the development process (Hakken et al 2010, Li et al 2011, Wong et al 2009).

Secondly, the impact of vicarious learning has supported other study findings, that peer support provides realistic practical information about the lived experience and is helpful in decision-making (Hughes et al 2009, Morton 2010a, 2010b). Increased homogeneity has been shown to foster cultural values and improve individuals' ability to relate to and accept information, as previously identified (Perry 2005). In contrast previous research has focussed on the context of planned vicarious learning. What this study has identified is the extent and breadth of eclectic vicarious learning. These positive and negative influences have been shown to have bearing on treatment decision-making. This study therefore builds upon other work in this area (Hughes et al 2009, Ormandy 2010, Paterson 2001).

The scale of vicarious learning revealed, and its impact upon treatment decision-making has implications for the delivery of pre-dialysis education. Previous studies have identified educational interventions that improve individuals' self-efficacy and self-management capacity (Hyera et al 2011, Yoo et al 2011). Additionally, the use of lay educators has also been shown to improve outcomes beyond HCP delivery (Berzins 2009). This study concurs with and has built upon these findings by creating new theory; to suggest that self-efficacy theory (Bandura 1977) has a time sequential dynamic. In contrast to Bandura's original theory, which focuses on mastery experience, this study contends that vicarious learning is a more powerful and effective means of information delivery during the pre-treatment phase.

Overall this study has identified three primary findings:

- Participant Action Research is an effective approach to the development and delivery of multidisciplinary and peer pre-dialysis education.
- Self-efficacy theory is an apposite foundation upon which to build a pre-dialysis educational curriculum.
- Vicarious learning is a significant influence on treatment decision-making and should be a fundamental element in pre-dialysis education development and delivery.

This thesis has used self-efficacy theory to guide the development of an educational intervention for individuals making treatment decisions in the pre-dialysis phase of renal failure. Pre-dialysis education is a complex intervention, which must be tailored to individuals' information needs to facilitate informed treatment decision-making. The link between self-efficacy theory and vicarious learning has been clearly identified as a key to achieving informed treatment choice. Government policy has focused on support for self-care in long-term conditions. Therefore, the role of the key elements identified should be recognised in future policy and research development. Living with renal failure and renal replacement therapy, is a major part of many individuals' lives. Increasing individuals' ability to cope and adjust through the delivery of education and on-going peer support will facilitate greater self-care. Vicarious learning needs to begin with the pre-dialysis education, based on self-efficacy theory. This can work to establish a solid

foundation for on-going education and treatment decision-making throughout the individuals' renal journey.

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Appendix 1: Literature Review studies from April 2009- Dec 2011.

| Author | i) Study Design | Population | Outcome Measures | Intervention Components | Findings | Limitations & Recommendations |
|---|---|--------------|---|---|--|--|
| Publication Year | ii) Sample Size | | | | | |
| Title | iii) Sample Population | | | | | |
| De Silva D. 2011 Helping people to help themselves: A review of the evidence considering whether it is worthwhile to support self-management | i) Literature Review ii) 550 (Systematic Reviews, RCTs & Large Observational Studies) iii) All patient groups | Unrestricted | No specific measures identified due to the diverse range of studies included. | Decision-making tools Problem solving Care plan partnership Goal setting Health promotion Motivational support Symptom monitoring Managing condition impact Pro-active follow-up Peer support & learning | Pro-active support of self-management and focusing on self-efficacy behaviour change, can impact on clinical outcomes and emergency service use. The pattern of service use changes rather than a reduction in use. | Limitations No quality weighting undertaken. Recommendations Need to focus on changing behaviours: involvement in decision-making, pro-active education, goal setting with follow-up, managing social, emotional and physical impacts of conditions. Training clinicians to support self-management. |

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| <p>Du S, Yuan C.</p> <p>2010</p> <p>Evaluation of patient self-management outcomes in health care: a systematic review</p> | <p>i) Systematic Review</p> <p>ii) 19 RCT's, participants 7275</p> <p>iii) Children & Adults</p> | <p>General & Long-term conditions</p> | <p>Self-efficacy</p> <p>Health behaviour/attitude</p> <p>Health status</p> <p>Health service utilization</p> <p>Quality of life</p> <p>Psychological indicators</p> | | <p>Self-efficacy was the most important evaluation indicator.</p> <p>Lorig et al's scale was the most popular and showed high internal consistency.</p> | <p>Limitations</p> <p>Evaluation of self-management in specific illness was not identified.</p> <p>Recommendations:</p> <p>In research and programmes effective evolution indicators are: self-efficacy, health behaviour/attitude, health status, health service utilisation, QOL and depression.</p> |
| <p>Goa WJ, Yuan CR.</p> <p>2011</p> <p>Self-management programme for</p> | <p>i) Literature Review</p> <p>ii) Six cancer self-management programmes</p> <p>iii) Adults</p> | <p>Cancer patients</p> | <p>Describe, compare and critique six self-management programmes that are commonly used to guide self-management for cancer patients</p> | | <p>Lack of the facilitators' training process, failure to assess the cultural differences and failure to cover all of the outcome measures</p> | <p>Recommendations:</p> <p>Researchers need to develop more individualised and dynamic research programmes to parallel advances in clinical research</p> |

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| cancer patients: a literature review | | | | | | practice. |
| <p>Haakan S, Parker D.</p> <p>2010</p> <p>Effectiveness of medical compared to multidisciplinary models of care for adult persons with pre-dialysis chronic kidney disease: a systematic review</p> | <p>i) Systematic Review</p> <p>ii) 4 studies</p> <p>iii) 1557</p> <p>iv) Adult</p> | CKD stage 4-5, pre-dialysis | <p>Study 1): Time to dialysis, illness knowledge, depression/anxiety, and social support.</p> <p>Study 2): Serum creatinine and clearance, health service use, mortality, medications use.</p> <p>Study 3): Blood pressure, anaemia, medications, access, dialysis start, time to dialysis.</p> | <p>Study 1): Health educator delivered, 90 min slide lecture, 60 page booklet, and telephone follow-up of 10 min /3weeks.</p> <p>Study 2): Multi-disciplinary CKD clinic, medication review and education, renal dietetic review low potassium and protein diet, social worker.</p> <p>Study 3): Multi-disciplinary CKD clinic, medication review and education, renal dietetic review low potassium and protein diet, social worker.</p> | <p>Study 1): Significant difference in time to dialysis ($p<0.0001$).</p> <p>Study 2): Creatinine and clearance NS, increased health service use in intervention group ($p<0.001$) due to increased CKD clinic visits.</p> <p>Study 3): BP decreased at follow-up visits, increase in PD selection. BP, metabolic and anaemia targets not achieved.</p> | Low number of articles included in the review, unable to perform meta-analysis. |

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| | | | Study 4): eGFR, Blood pressure, lipid abnormalities. | Study 4): GP review and community based nursing care, medication management and education, illness related education, dietetic advice on self-care, social worker support. | Study 4): Delayed progression of CKD, improved systolic ($p<0.05$), and diastolic ($p <0.01$). Total cholesterol and LDL improved ($p<0.01$). | |
| <p>Hubbard G, Illingworth N, Rowa-Dewar N, Forbat L, Kearney N.</p> <p>2010</p> <p>Treatment decision-making in cancer care: the role of the carer</p> | <p>i) Three serial semi-structured interviews with a thematic approach to data analysis</p> <p>ii) Sixty-six patients and 43 carers</p> <p>iii) Adults</p> | Cancer patients and their carers | To explore the role of the carer in treatment decision-making. | | <p>Carers can become: conduits for information during consultations: facilitators during deliberations, helping patients to consider which treatment or whether to have treatment; models fail to acknowledge carer involvement</p> <p>Limitation: Findings derived from a broader study.</p> <p>Limited generalisability and causal relationship of carer involvement with improved decision-making/care not explored.</p> <p>Recommendation: Development of communication skills for health care professionals, inclusion of</p> | |

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| | | | | | | partners/carers and family without breaching confidentiality. |
| <p>Hughes J, Wood E, Smith G.</p> <p>2009</p> <p>Exploring kidney patients' experience of receiving individual peer support</p> | <p>i) Qualitative telephone interview</p> <p>ii) 20 participants</p> <p>iii) Adult</p> | Kidney patients who had received peer support | Individual peer support | | <p>Valued for its practical information about the lived experience, which helped treatment decision-making.</p> <p>Peer supporters provided: empathy, understanding, positive role model, reduced feelings of isolation, increased adaptation and coping and increased sense of empowerment.</p> <p>A brief meeting was as impactful as group support.</p> | <p>Limitations:</p> <p>Single centre retrospective study.</p> <p>Potential bias toward positive impact of peer support when being interviewed specifically about the experience.</p> <p>Recommendations:</p> <p>Further research to understand the psychosocial processes involved and the impact on maximising patient benefits.</p> |

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| <p>Hyera Y, Chun J K, Yeonsoo J, Mi-Ae Y.</p> <p>2011</p> <p>Self-efficacy associated with self-management behaviours and health status of South Koreans with chronic diseases</p> | <p>i) Cross sectional descriptive & correlational design and administrated questionnaire</p> <p>ii) 322</p> <p>iii) Adults</p> | <p>Arthritis, diabetes or hypertension</p> | <p>To examine differences in self-management behaviours and health status according to the level of self-efficacy (high, moderate and low)</p> | | <p>Level of self-efficacy was associated with self-management behaviours ($P < 0.05$) and with better health status indices ($P < 0.001$) except fatigue ($P < 0.277$). The mean age (Mean \pm standard deviation, 53.71 ± 12.60), the percentage of high level of education (62.4%) and the level of employment (51.4%) were significantly higher in high self-efficacy group than in low self-efficacy group or moderate self-efficacy group.</p> | <p>Limitations:</p> <p>Single centre self-report methodology</p> <p>Cross-sectional design negates ability to identify causal links.</p> <p>Recommendations:</p> <p>Self-efficacy-enhancing interventions can be beneficial for Korean chronic patients to improve their self-management behaviours and health status.</p> <p>RCT study in diverse locations to</p> |
| <p>Li T, Wu HM, Wang F, Huang CQ, Yang M, Dong BR, Liu GJ.</p> <p>2011</p> | <p>i) Systematic Review: 2 studies</p> <p>ii) 207</p> <p>iii) Adult</p> | <p>Diabetic kidney disease (DKD)</p> | <p>Primary:</p> <p>Biochemical, mortality, changes in kidney function.</p> <p>Quality of Life</p> <p>Secondary:</p> | <p>Study 1: five weekly and one booster, 2.5 hour education sessions. Delivered by a diabetes manager, including: behaviour change, diabetes self management, diet, exercise, medication,</p> | <p>Study 1: Statistically significant improvement in: quality of life for diabetic symptom ($P < 0.001$), health perception ($P < 0.002$).</p> | <p>Only two articles included in the systematic review.</p> <p>Risk of bias, small sample size, inadequate</p> |

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| Education programmes for people with diabetic kidney disease (Review) | | | <p>Blood pressure, HbA1c, lipids.</p> <p>Knowledge of DKD, self-efficacy, behaviour change.</p> | <p>psychological and physical issues of diabetes discussed.</p> <p>Study 2: twelve month programme of routine care plus 3x weekly education sessions for HD and monthly for PD, delivered by a diabetes nurse specialist, including: diabetes self-care, motivational coaching, and diabetes education.</p> | <p>At 3 month follow-up: Significant difference in quality of life (ANOVA:F (1,97)=9.33; $P<0.01$)</p> <p>Study 2: Improved: knowledge of diabetes and microalbuminuria, improved total self-efficacy at the end of treatment but not at 3-month follow-up.</p> <p>Improved diabetes treatment care behaviours but not HbA1c control. Improved behaviour measures but no significant difference by follow-up.</p> | <p>randomisation methods, selective results reporting.</p> |
| Morton R, Devitt J, Howard K, Anderson K, Snelling P, Cass A. | i) Thematic Synthesis of semi-structured interviews | Chronic Kidney Disease on Dialysis and transplant | Patients perceptions of treatment characteristics and the influence on | | Participants preferred treatment that: enhanced freedom and autonomy were | <p>Limitation:</p> <p>Only small home haemodialysis numbers included, so</p> |

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| <p>2010 a</p> <p>Patient views about treatment of stage 5 CKD: A qualitative analysis of semi-structured interviews</p> | <p>ii) 95</p> <p>iii) Adult</p> | | <p>treatment decision-making</p> | | <p>convenient, effective and simple.</p> <p>Treatment with minimal impact on lifestyle influenced decision-making.</p> | <p>may limit breadth of data saturation.</p> <p>Recommendations:</p> <p>Education should focus on the characteristics of treatment options and the impact on lifestyle.</p> |
| <p>Morton R, Howard K, Snelling P, Webster AC.</p> <p>2010 b</p> <p>The views of patients and carers in treatment decision-making for chronic kidney disease: systematic review and thematic synthesis of</p> | <p>i) Systematic Review & Thematic Synthesis</p> <p>ii) 18 studies, with 462 participants in total</p> <p>iii) Adult</p> | <p>Chronic Kidney Disease</p> | <p>Participants perception and experience of treatment decision-making</p> | | <p>Four main themes: confronting mortality, lack of choice, gaining knowledge of options, weighing alternatives.</p> <p>Peers experience influenced decision-making. Access creation inhibited self-care choices, maintenance of status quo results in patients remaining on initial therapy.</p> | <p>Limitations: Lack of ethnic minority representation.</p> <p>Recommendations: Incorporation of peer educators/mentors, education delivery when eGFR <30mls/min/1.72m², formal care pathway.</p> |

| qualitative studies | | | | | | |
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| Morton R, Howard K, Webster A, Snelling P 2011a Patient Information about Options for Treatment (PINOT): a prospective national study of information given to incident CKD Stage 5 patients | i) A prospective national multi-centre study ii) 66 renal units, 721 participants iii) Adult | Incident pre-emptive transplant, dialysis and conservatively managed renal patients | Information given to the study population over a three month period | | Most patients were informed about treatment options but at a late stage when eGFR <13mls/min/1.73m2 Information was more prevalent in-patient known for more than three months and in smaller units. | Limitations: Potential bias in unit self-reporting of information delivery Recommendations: Earlier education and support for informed Decision-making may help to optimize the uptake of pre-emptive transplantation and home dialysis therapies. |
| Morton, R et al 2011b | i) Mixed methods: Dialysis characteristics ranking | Pre-dialysis patients, dialysis patients and family caregivers | Ranked dialysis characteristics Focus group thematic analysis Between group | No intervention | 28 dialysis characteristics identified. Both patient groups agreed most important | Limitation: Study conducted in a unit actively promoting home dialysis and with more highly educated patients |

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| <p>Characteristics of dialysis important to patients and family caregivers: a mixed methods approach</p> | <p>Focus Groups</p> <p>ii) 34</p> <p>iii) Adult</p> | | <p>comparison</p> | | <p>characteristics were: (i) survival, (ii) convenience & (iii) dialysis free days.</p> <p>For caregivers the most important characteristics were: (i) convenience of dialysis, (ii) respite & (iii) ability to travel.</p> | <p>than the broader population, thus reducing generalisability.</p> <p>Recommendation: Future planning should reflect the priorities identified and support home dialysis and respite for caregivers.</p> |
| <p>Wong F, et al</p> <p>2009</p> <p>Evaluation of a nurse-led management programme for chronic kidney disease: A randomized controlled trial</p> | <p>i) RCT</p> <p>ii) 98</p> <p>iii) Adult</p> | <p>Haemodialysis patients</p> | <p>Diet , fluid, dialysis & medication concordance.</p> <p>Kidney Disease Quality of Life Questionnaire</p> <p>La Monica-Oberst Patient Satisfaction Scale</p> <p>Symptom Control</p> <p>Complication Control</p> <p>Health service utilisation</p> | <p>Staff Training: Renal nurses; 24 hours including, 8 hours theoretical input, 4 hours case training & review and 4 hours guided study.</p> <p>Patient Intervention:</p> <p>Control Group: usual care only.</p> <p>Intervention: Disease management programme and usual care. Four C's model: comprehensiveness,</p> | <p>At baseline: no significant differences between groups apart from sleep.</p> <p>At 7 weeks: Diet adherence, sleep, symptoms, staff encouragement, overall health and satisfaction significantly improved in intervention group (p<0.05)</p> <p>At 13 weeks: Sustained effect on CAPD adherence</p> | <p>Limitation: Small sample size.</p> <p>Short follow-up</p> <p>CAPD patients so limited generalisability</p> <p>Recommendation: Skills mix using specialist and general nurses demonstrates patient improvement in diet adherence.</p> |

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| | | | | collaboration, coordination and continuity. | degree, sleep, symptom and effect of kidney disease. | |
| Yoo H, et al 2011 Self-efficacy associated with self-management behaviours and health status in South Koreans with chronic diseases | i) Descriptive Correlative Questionnaire Study ii) 322 iii) Adult | Arthritis Diabetes Mellitus Hypertension | Self-efficacy, self-management and health behaviours questionnaires: Personal Data Questionnaire Chronic Disease Self-Efficacy Scale Exercise Behaviour Communication with Physician Cognitive Symptom Management Visual Numeric Pain Scale The Fatigue Scale Patient Health Questionnaire Depression Scale | No intervention | Self-efficacy was associated with self-management behaviours ($p<0.001$), improved health status indices ($p<0.001$), except fatigue ($P<0.277$). Significantly higher: Mean age (Mean \pm standard deviation, 53.71 ± 12.60), level of education (62.4%), & employment (51.4%) in the high self-efficacy group compared to moderate and low self-efficacy groups. | Limitation: Single setting, convenience sample using self-report questionnaires limiting generalisability. Causal link not established. Recommendation: Further research to explore factors affecting any relationship between self-efficacy and fatigue. RCT to explore the effect of self-efficacy on self-management behaviours and/or health status. |

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| | | | Health Distress Scale Stanford Health Assessment Questionnaire 8 item Disability Scale | | | |
| Zamperion A, Ormandy P, Elseviers M, Kafkia T. 2009 Comparison of nephrology nursing interventions across five European countries | i) Questionnaire ii) 172 Renal Centres iii) Renal nurses | Renal Nurses | Renal nursing interventions | | Renal nursing interventions vary significantly across Europe. They develop in an ad hoc manner in response to pressure for: advanced nursing roles, staff shortage and increased patient demand. | Limitations: Respondents perception of the questions result in inconsistencies and makes comparison potentially erroneous. Non- standardised nomenclature across European nursing limits reliability of responses. Recommendation: Capturing measurable nursing indicators and simultaneous patient outcomes and quality of care have the potential to advance renal nursing role |

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| | | | | | | expansion and extension by clearly identifying their contribution to patient care. |
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Appendix 2: Ethics Committee and R&D Approval Documents



University Hospitals **NHS** Coventry and Warwickshire

NHS Trust

University Hospital
Clifford Bridge Road
Walsgrave
Coventry
CV2 2DX

Research & Development Department
Associate Medical Director (R&D): Professor Steve Thornton – Tel: 024 7696 6195
Personal Assistant: Karen MacKillop – Tel: 024 7696 6195
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R&D Divisional Finance Manager: Chris Moore – Tel: 024 7696 6198
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www.uhcv.nhs.uk

2nd July 2007

Our Ref: ST/KMK/KM04/0607
MREC Ref: 07/Q2802/53

Kate McCarthy
Renal Research Sister
Renal Department
University Hospital
Coventry
CV2 2DX

Dear Kate

Study Title: Turning Information into Education. What Should a Pre-dialysis Education Module Entail?

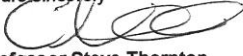
Thank you for submitting the above study for consideration by the Research & Development Office. I am pleased to inform you that the study has been approved and your research activity is now covered by NHS indemnity as set out in HSG(96)48. For reference, the approval number is: KM04/0607 and it would be appreciated if you could quote the R&D reference in all future correspondence.

May I take this opportunity to remind you that, as a researcher, you must ensure that your research is conducted in a way that protects the dignity, rights, safety and well-being of participants. Trust R&D Approval assumes that you have read and understand the Research Governance Framework and accept that your responsibilities as a researcher are to comply with it, the Data Protection and Health & Safety Acts.

Your project may be subject to ad hoc audit by our department to ensure these standards are being met.

The Trust wishes you every success with your project.

Yours sincerely


Professor Steve Thornton
Associate Medical Director of R&D

U/Research Project Management/Research Projects/2007/07/KM04/0607/Non-Commercial Approval
Letter to Kate Mearns 02.07.07

Chief Executive: David Roberts

Chairman: Bryan Stoten



National Research Ethics Service

Coventry Research Ethics Committee

2nd floor West Wing
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

26 June 2007

Telephone: 024 7696 7529

Facsimile: 024 7696 5033

Mrs Kate McCarthy
Renal Research Sister
University Hospitals NHS Trust
ACG50006, West Wing, University Hospitals NHS Trust
Clifford Bridge Road
Coventry
CV2 2DX

Dear Mrs McCarthy

Full title of study: Turning Information into Education. What should a pre-dialysis education module entail?
REC reference number: 07/Q2802/53

Thank you for your letter of 12 June 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|-----------------|---------------|---------------|
| Application | A&B | 23 April 2007 |
| Investigator CV | Kate McCarthy | 23 April 2007 |
| Protocol | Version 1 | 19 April 2007 |

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

| | | |
|---|-------------------|---------------|
| Covering Letter | K McCarthy | 12 April 2007 |
| Summary/Synopsis | Version 1 | 19 April 2007 |
| Interview Schedules/Topic Guides | Version 1 | 19 April 2007 |
| Participant Information Sheet | Version 1.1 | 11 June 2007 |
| Participant Consent Form | Version 1 | 19 April 2007 |
| Response to Request for Further Information | Letter K McCarthy | 12 June 2007 |
| Academic Supervisor | Dr J Sturt | 23 April 2007 |
| Checklist | | |

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from
<http://www.rdforum.nhs.uk/rdform.htm>.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:


<https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx>

We value your views and comments and will use them to inform the operational process and further improve our service.

| | |
|-------------|--|
| 07/Q2802/53 | Please quote this number on all correspondence |
|-------------|--|

With the Committee's best wishes for the success of this project

Yours sincerely


Mr Stephen Keay
Chairman

Email: pauline.pittaway@uhcw.nhs.uk

Enclosures: Standard approval conditions SL-AC2

Copy to: Ms Kate Hughes, University of Warwick
R&D office for UHC&W NHS Trust



National Research Ethics Service

Birmingham, East, North and Solihull Research Ethics Committee

REC Offices
Prospect House
Fishing Line Road
Enfield
Redditch
B97 6EW

Tel: 01527 582534
Fax: 01527 582540

17 January 2011

Mrs Kate McCarthy
Renal Research Sister
University Hospitals NHS Trust
Renal Research Sister
20 Lant Close
~~Berkswell~~
Coventry
CV4 9TG

Dear Mrs McCarthy

Study title: The implementation, trialling and evaluation of educational intervention components for pre-dialysis patients with established renal failure.
REC reference: 09/H1206/82
Amendment number: AM01
Amendment date: 09 January 2011

The above amendment was reviewed by a Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

| Document | Version | Date |
|--|--|-----------------|
| Interview Schedules/Topic Guides | Appendix 6 - 12 month schedule - Version 1.0 | 04 January 2011 |
| Notice of Substantial Amendment (non-CTIMPs) | | 09 January 2011 |
| Covering Letter | | 04 January 2011 |

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| | | |
|----------------------------------|---|-----------------|
| Interview Schedules/Topic Guides | Appendix 7 - Post commencement schedule - Version 1.0 | 04 January 2011 |
|----------------------------------|---|-----------------|

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

| | |
|--------------|--|
| 09/H1206/82: | Please quote this number on all correspondence |
|--------------|--|

Yours sincerely



Mrs Karen Green
Committee Co-ordinator

E-mail: Karen.Green@westmidlands.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *R&D, University Hospitals Coventry & Warwickshire NHS Trust*

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University Hospitals
Coventry and Warwickshire



NHS Trust

University Hospital
Clifford Bridge Road
Walsgrave
Coventry
CV2 2DX

Tel: 024 7696 4000
Fax: 024 7696 6056
www.uhcw.nhs.uk

2nd July 09

Our Reference: KM059409
MREC number: 09/H1206/82

Mrs Kate McCarthy
Renal Research Sister
20 Lant Close
Berkswell
Coventry, CV49TG

Dear Kate,

Study Title: The Implementation, trialling and evaluation of educational intervention components for pre-dialysis patients with established renal failure

Thank you for submitting the above study for consideration by the Research & Development Office. I am pleased to inform you that the study has been approved on the basis that the University of Warwick are the sponsor, and your research is covered by NHS indemnity as set out in HSG(96)48. For reference, the approval number is: KM059409 and it would be appreciated if you could quote the R&D reference in all future correspondence.

May I take this opportunity to remind you that, as a researcher, you must ensure that your research is conducted in a way that protects the dignity, rights, safety and well-being of participants. Trust R&D Approval assumes that you have read and understand the Research Governance Framework and accept that your responsibilities as a researcher are to comply with it, the Data Protection and Health & Safety Acts.

Your project may be subject to ad hoc audit by our department to ensure these standards are being met.

The Trust wishes you every success with your project.

Yours sincerely

Professor Steve Thornton
Associate Medical Director of R&D

Cc: Mrs Ceri Jones, R&D Services Manager, University Hospital

Chief Executive: Malcolm Stamp CBE

Chairman: Philip Townshend

Tell us what you think about our service, visit www.uhcw.nhs.uk

Missed appointments cost our hospitals nearly £4 million a year. Please help us reduce this by ensuring you attend yours or call 0800 252060 to change your date/time.



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Dear Mrs McCarthy

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R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

| | |
|--------------|--|
| 09/H1206/82: | Please quote this number on all correspondence |
|--------------|--|

Yours sincerely



Mrs Karen Green
Committee Co-ordinator

E-mail: Karen.Green@westmidlands.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *R&D, University Hospitals Coventry & Warwickshire NHS Trust*

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority.
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Appendix 3

PARTICIPANT INFORMATION SHEET

Action Research Participants

STUDY TITLE

The implementation, trialling and evaluation of educational intervention components for pre-dialysis patients with established renal failure.

INVITATION PARAGRAPH

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

PURPOSE OF STUDY

The purpose of the study is to improve the education available to renal patients by establishing the amount and type of information patients find useful.

This study is being carried out as part of a Doctorate of Philosophy at the University of Warwick. The research aims to identify:-

- How much the staff giving information to patients affects patient's education and choice of treatment?
- Patients experience of education about their condition and its treatment, and what they did and didn't find useful.
- The educational needs of patients who started dialysis as an emergency, without prior experience of renal failure.

WHY HAVE I BEEN CHOSEN?

You have been chosen for your experience and expertise in the field of pre-dialysis patient education.

In total about 14 action research participants will be invited to participate, including;

- Chief investigator, renal consultant, clinical nurse specialists, renal dietician, renal social worker, renal clinical psychologist, haemodialysis nurse, peritoneal dialysis nurse, nephrology medicine nurse, patient information librarian and two renal patients.

DO I HAVE TO TAKE PART

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your work status.

PARTICIPANT INFORMATION SHEET CONTINUED:
Action Research Participants

IF I TAKE PART WHAT WILL I HAVE TO DO?

Action Research Meetings: Following initial establishment of the action research group, meetings will be held three monthly from May 2009 through to October 2010. These action research meetings will form the first of two data collection opportunities to address the research questions. These meetings will last for 120 minutes and be audio-recorded and subsequently transcribed. The group will identify and assess the appropriateness of existing nationally available patient education and decision-making resources for use within UHCW using the National guidelines for structured education in diabetes as the benchmark. These guidelines (ref) require clinical teams delivering patient education to have an a) an agreed philosophy (e.g. patient centred, staged delivery, empowering) b) a written curriculum c) trained educators able to employ established adult learning/behavioural science theories d) a quality assurance process e) an audit process. Outside of the action research meetings, meetings will be held fortnightly with specialists delivering the educational intervention components to provide support, evaluate feedback and address issues that may arise. This data will be collected as field notes and fed back into the action research meetings.

POSSIBLE BENEFITS FROM TAKING PART?

The greater variety in the types of education available to patients will increase patient's education choices. As an action research participant you will have a direct influence on the education components implemented and their evaluation for use in your everyday practice. For future renal healthcare professionals and patients the study findings will hopefully improve the understanding of the type, amount and presentation of education patients find useful at differing stages of their treatment so that an educational toolkit can be created. The information we get from this study may help us educate future renal patients more effectively.

CONFIDENTIALITY

If you consent to take part in this research, action research participants will be allocated a study number when they enrol for the study, a list of participants and study numbers will be known only to the principle investigator and stored securely and separately from the study data. Thus all audio and transcribed data will be anonymised. Pseudonyms will be generated for qualitative data reporting and discussion to protect the anonymity of participants.

RESULTS OF THE RESEARCH STUDY

The results will be published in specialist renal publications as well as at conferences, lectures and seminars as well as renal patient publications. The results will also provide the basis for a PhD Thesis. No single individual will be identifiable from the published data.

PARTICIPANT INFORMATION SHEET CONTINUED:
Action Research Participants

STUDY REVIEW

University Hospitals NHS Trust's Research & Development department and the Local Research and Ethics Committee (LREC) have reviewed the study.

WHAT IF SOMETHING GOES WRONG?

The non-invasive nature of the research means that the risk of anything going wrong is very unlikely, but may possibly be related to issues raised within the interview. The interviewer has experience of managing group meetings and will be able to respond appropriately to any concerns and make referrals onto further support if required.

COMPLAINTS

If taking part in this study harms you there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal claim. Regardless of this, if you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, these can be directed to;

Sharon Wyman
Complaints Manager for the Trust
Rotunda General Nursing Office
University Hospitals
Clifford Bridge Road
Coventry
CV2 2DX
Telephone 024 76965198

CONSENT COPIES

If you decide to consent to the research you will be given a copy of both this Participant Information Sheet and the Consent form. A copy of your consent form will be kept by the chief investigator.

CONTACT FOR FURTHER INFORMATION

Sr Kate McCarthy
Renal Research Offices
ACG50007, West Wing
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

Telephone 024 76965102
E-mail Kate.Mccarthy@warwick.ac.uk

Version 1.0 11/05/09

APPENDIX 3 Continued

PARTICIPANT INFORMATION SHEET **Intervention Participants**

STUDY TITLE

The implementation, trialling and evaluation of educational intervention components for pre-dialysis patients with established renal failure.

INVITATION PARAGRAPH

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

PURPOSE OF STUDY

The purpose of the study is to improve the education available to renal patients by establishing the amount and type of information patients find useful.

This study is being carried out as part of a Doctorate of Philosophy at the University of Warwick. The research aims to identify:-

- How much the staff giving information to patients affects patient's education and choice of treatment?
- Patients experience of education about their condition and its treatment, and what they did and didn't find useful.
- The educational needs of patients who started dialysis as an emergency, without prior experience of renal failure.

WHY HAVE I BEEN CHOSEN?

You have been chosen because you are registered on a renal database and have established kidney disease.

In total about 60 patients will be invited to participate;

- Group 1. 60 patients who are receiving pre-dialysis care at University Hospitals NHS Trust.
- Group 2. 20 patients', who are calculated to require dialysis within the next twelve months, will be invited to participate in three interviews.

DO I HAVE TO TAKE PART

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

PARTICIPANT INFORMATION SHEET CONTINUED:
Intervention Participants

IF I TAKE PART WHAT WILL I HAVE TO DO?

Group 1 participants will be required to complete two questionnaires when they are first seen, again after six months and then one month after starting dialysis treatment. The questionnaires take about 40 minutes to complete. Group 2 participants will be required to complete the same questionnaires as group 1. You would also be requested to attend three interviews that will last for 60-90 minutes, the first interview will be when you are first seen in pre-dialysis clinic, the second six months after first being seen in clinic and then a further interview one month after you start dialysis treatment. You will be interviewed by the research nurse about your experience and views on education for patients with kidney disease. At this interview you will be asked to give some basic information regarding age, ethnicity, marital and work status as well as any other illnesses. The interview will be recorded and conducted at a time and place convenient to you.

POSSIBLE BENEFITS FROM TAKING PART?

There are no direct benefits to you by taking part in the study. However, for future patients the greater variety in the types of education available to patients will increase patient's education choices. The study findings will hopefully improve the understanding of the type, amount and presentation of education patients find useful at differing stages of their treatment so that an educational toolkit can be created. The information we get from this study may help us educate future renal patients more effectively.

CONFIDENTIALITY

If you consent to take part in this research, your response will be given a study number and data will be held on a password protected computer and kept in a locked office. Your name will be kept in a separate file away from that containing your answers. Your name will not appear on any research work and will be known only to the main researcher.

RESULTS OF THE RESEARCH STUDY

The results will be published in specialist renal publications as well as at conferences, lectures and seminars as well as renal patient publications. The results will also provide the basis for a PhD Thesis. No single individual will be identifiable from the published data.

STUDY REVIEW

University Hospitals NHS Trust's Research & Development department and the Local Research and Ethics Committee (LREC) have reviewed the study.

PARTICIPANT INFORMATION SHEET CONTINUED:
Intervention Participants

WHAT IF SOMETHING GOES WRONG?

The non-invasive nature of the research means that the risk of anything going wrong is very unlikely, but may possibly be related to issues raised within the interview. The interviewer has many years experience of managing acute and chronic renal patients and will be able to respond appropriately to any concerns and make referrals onto further support if required.

COMPLAINTS

If taking part in this study harms you there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal claim. Regardless of this, if you have any cause to complain about any aspect of the way you have been approached or treated during the course of this study, these can be directed to;

Sharon Wyman
Complaints Manager for the Trust
Rotunda General Nursing Office
University Hospitals
Clifford Bridge Road
Coventry
CV2 2DX
Telephone 024 76965198

CONSENT COPIES

If you decide to consent to the research you will be given a copy of both this Participant Information Sheet and the Consent form. A copy of your consent form will be placed in your medical records and a copy will be held by the chief investigator.

CONTACT FOR FURTHER INFORMATION

Sr Kate McCarthy
Renal Research Offices
ACG50007, West Wing
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

Telephone 024 76965102
E-mail Kate.Mccarthy@uhcw.nhs.uk

Version 1.0 11/05/09

Appendix 4

Action Research Participant:

Participant Identification Number:

CONSENT FORM

Title of project:

The implementation, trialling and evaluation of educational intervention components for pre-dialysis patients with established renal failure.

Name of Researcher:

Kate McCarthy

1. I confirm that I have read and understood the Information Sheet 1.0 dated 11.05.2009 for the above study and have had the opportunity, to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without employment status or legal rights affected.
3. I understand that meetings will be audio recorded and field notes may be looked at by the researcher or the regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to have access to these records.
4. I agree to take part in above study.

☐☐☐☐

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

Researcher

Date

Signature

1 for participant

1 for researcher

Version 1.0 11/05/09

Intervention Participant:

Participant Identification Number:

CONSENT FORM

Title of project:

The implementation, trialling and evaluation of educational intervention components for pre-dialysis patients with established renal failure.

Name of Researcher:

Kate McCarthy

- | | |
|---|--------------------------|
| 1. I confirm that I have read and understood the Information Sheet 1.0 dated 11.05.09 for the above study and have had the opportunity, to ask questions. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without any medical care or legal rights affected. | <input type="checkbox"/> |
| 3. I understand that sections of any of my medical notes may be looked at by the researcher or the regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records. | <input type="checkbox"/> |
| 4. I agree to take part in Group 1 only of the above study. | <input type="checkbox"/> |
| 5. I agree to take part in Group 1 or 2 of the above study. | <input type="checkbox"/> |

Name of patient

Date

Signature

Name of person taking consent

Date

Signature

Researcher

Date

Signature

1 for patient

1 for researcher

1 to be kept in notes

Version 1.0 11/05/09

Appendix 5: Example Participant Newsletter



Summer 2011 Research Newsletter
Study: The role of theory in pre-dialysis patient education and treatment decision-making.

I would like to thank everyone who has completed the interviews for a second and third time, the end is in sight!
Without your help this research would mean nothing.

-All twenty interview participants have now completed the second round of interviews and seven have completed all three interviews.
-Interview participants continue to be followed-up at six months and twelve months.
-The twelve month interviews remain just as important as participants are then in a position to really judge if the education received was appropriate.

Changes made to the patient education session are being reviewed very positively by those patients attending.

Patients' ideas to improve the kidney education provided is being fed back to the relevant departments.

I like to thank people for taking the time to complete all three interviews. The information gained from them gives a clearer picture of your pre-dialysis experience.

I have enclosed with this newsletter the Renal Service Patient Directory that has been created as a direct result of this research and is now available to all renal patients and can be found on the hospital website: <http://www.ghow.nhs.uk/low-services/renal-services/renal-services>

As Albert Einstein said
"If we knew what we were doing it would not be called research, would it?"

Kate McCarthy
Nurse Researcher/PhD Student
014 75955102 (Voice mail)
Kate.mccarthy@glasgow.ac.uk

Appendix 6: Needs Assessment Study, Coding Hierarchy

| Theme | Category | Sub-Category |
|---|--------------------------------|--------------------------|
| Decision-making information mediated through relationships | | |
| | Conflicting advice | |
| | Confidence in HCPs roles | |
| | Dietician | |
| | Doctors | |
| | Family | |
| | Nurses | |
| | Patient contact | |
| | | Positive patient contact |
| | | Negative patient contact |
| | Trust & honesty | |
| Modes of information delivery | | |
| | DVD of treatment choices | |
| | Education information received | |
| | Education information needs | |
| | Family information | |
| | | Education to share |
| | | Carer information |
| | 'Help' booklet | |
| | Internet | |
| | Patient information leaflets | |
| | Preferred education format | |
| | Written information | |
| | | Reference material |
| Influences on patient decision-making | | |
| | Anxiety | |
| | | Stress |
| | Coping mechanisms | |
| | Depression | |
| | Fear | |
| | Limbo | |
| | Symptoms | |
| | | |

| | | |
|---|-----------------------------|----------|
| | | |
| | | |
| Patient decision-making criteria | | |
| | Autonomy | |
| | Body image | |
| | Control | |
| | Fear | |
| | Lifestyle | |
| | | Work |
| | | Family |
| | Lack of treatment awareness | |
| | Loss of control | |
| | Negative patient contact | |
| | Quality of life | |
| | Self-management | |
| | | Diabetes |
| Outcomes of decision-making | | |
| | Concordance | |
| | Decision regret | |
| | Own decision not family | |
| | Unaware of other options | |

Appendix 7

| First Interview Potential Topics |
|---|
| Individuals' experience of being diagnosed with kidney disease and the circumstances surrounding this. |
| Individuals' feelings about needing treatment for their kidney disease, when they were told and now. |
| What helped their transition (if any) from their initial feelings to their present feelings and what else if anything could have helped? |
| What is it that helps them to cope? |
| How confident are individuals that they understand their kidney diagnosis? (<i>Reassure they are not expected to understand</i>) |
| What do individuals understand about the treatment options and what are their feelings about those options? (<i>Reassure they are not expected to know these</i>) |
| If they have decided on an option what was influential in coming to that decision? |
| Is there anything they feel they need to know at the present time? |
| What educational input if any have individuals received so far? |
| How do individuals feel about the information they have received so far? |
| What if anything is particularly important or helpful at the moment? |
| What are individuals' feelings towards their kidney disease and their future? |

| Second Interview Potential Topics |
|---|
| How the participant had been since the previous interview visit. |
| Were there any changes they had noticed in their kidney disease that were causing issue or problems, and if so how were they feeling, coping, and how if at all things had been resolved. |
| What support was available to the individual or what would be helpful right now? |
| Do individuals have any anxieties or concerns at the moment? |
| How do participants feel about their kidney disease and the treatment options? |
| If a decision has been made what influenced them in coming to that decision. |

| Third Interview Potential Topics |
|---|
| How the participant had been since the previous interview visit. |
| How do they feel about their kidney disease at the moment; are there any issues and if so how are they being dealt with? |
| How do individuals feel i) physically is there an increase in symptom burden; ii) mentally due to their deteriorating condition with worsening biochemistry and treatment being imminent. |
| What education have they received since last the last interview, how and why was it helpful or otherwise. |
| With hindsight how well has the timing of education matched their needs? What was most helpful; what else would have been helpful; why and when? |
| Has a treatment choice been decided and how do they feel about it? |
| What if any anxieties or concerns do participants have at this time? |
| How do individuals feel about the future? |

Appendix 8

Loss to Follow-up

At the second and third interview stage, one participant was visiting family in India whilst his renal function remained stable, and another participant had become too poorly to continue with the study. At the third interview stage, one participant felt she had no new information to add, so declined the third interview. Finally, another participant was diagnosed with cancer shortly after his second interview and died prior to the third interview stage.